

PERCEPTIONS OF PARENTS AND CAREGIVERS REGARDING THE SPECIAL
NEEDS OF CHILDREN AT SUNSHINE DAY CARE CENTRE IN WALVISBAY

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ABSTRACT

There are many challenges in raising and caring for a child with special needs. Each barrier experienced, is challenging in, and of itself for parents and caregivers. When a parent or caregiver learns that a child has a disability or chronic illness, it takes them on an unexpected journey that requires constant empathy and sensitivity, towards the child. These feelings are often filled with strong emotion and difficult choices. Children with special needs are framed within the discourse of stigma constructed by the society in which the child is raised. Such families and their children are affected by the beliefs, values, and attitudes situated in the narratives of the community.

This thesis set out to examine some of the difficulties and the perceptions of parents and caregivers with regards to the special needs of children at Sunshine Day Care Centre in Walvis Bay. Furthermore, it aimed to gain insight and a better understanding as to whether parents and caregivers know how to care for, and protect children with special needs.

This qualitative study was framed within, a phenomenological paradigm, employing a purposive sampling method. Fifteen parents and family caregivers were selected, a further five employed caregivers of the Day Care Centre were also included in the sample.

Guided by the theoretical underpinnings, the researcher conducted one-on-one in-depth interviews to understand the meaning that parents or caregivers gave to the everyday life of their children with special needs. The empirical findings revealed that the process of acceptance with regards to the special needs of child is unique for each parent or caregiver. A lack of medical diagnoses in some instances also hindered and influenced the process to manage them. It was further revealed that not all parents and caregivers grasped the severity of the special needs requirement of their children at the Centre and that therapeutic interventions were seldom sought to deal with emotional stressors. Parents and caregivers often have unrealistic expectations for their children. Parental or caregiver satisfaction with the services and assistance from the Centre was overwhelming. All the parents and

caregivers and employed caregivers received their training and guidance on how to care for children with special needs from the Centre. Based on the findings it were concluded that the working partners responsible for the Day Care Centre, the responsible government ministries and other stakeholders become more involved in raising awareness and offering and fostering support services to the community on disability issues.

This should start from the antenatal stage with the prospective mothers, to educate them about, and create awareness around potential birth defects, to identify help and treatment for their children as early as possible. A troubling finding of this study revealed that parents and caregivers were unaware and ill-informed about resources to assist them in their tasks of care. The need for a support group for parents or caregivers of children with special needs emerged as an imperative, and would be greatly valued to strengthen them emotionally and provide the opportunities to draw on and cement best practices amongst parents. These best practices encompass skills in decision-making, planning and influencing policymaking in their community.

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DEDICATION

This work is dedicated to all people in Namibia living with disabilities.

DECLARATION

I, Barbara Van Rooyen hereby declare that this study is my own work and is a true reflection of my research, and that this work, or any part thereof has not been submitted for a degree at any other institution.

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CHAPTER ONE

CONTEXTUALIZATION AND ORIENTATION OF THE STUDY

1 Introduction

The World Health Organisation (WHO) report on disability emphasized how a person's environment influences the experiences and the extent of disability WHO (2011). This World report on disability charts the steps that are needed to improve participation and inclusion of people with disabilities. Against a stark background they declare that people with disabilities have poorer health outcomes, lower education achievements, less economic participation, and higher rates of poverty than people without disabilities. These difficulties are exacerbated in less advantaged communities. A view that has been underscored by different authors who further underline the influence of cultural beliefs in the community on children with special needs and the influence it has on parenting or care-giving of such children. Green (2007) confirms that the uniformity of authors on this issue, and iterate that it is a burden, and it causes combating emotional anxieties and stress by the parents and caregivers, a consistent thread throughout the literature.

Green (2007) subsequently reported that, despite all the negativity around parenting a child with special needs in the modern society, some parents and caregivers manage to identify positive experiences in parenting a child with special needs. Parents and caregivers and community efforts that provide services to children with special needs need to be supported and appreciated.

In the absence of a dedicated school for children with special needs, and a training facility for parents or caregivers in Walvis Bay, a community initiative was launched. Such initiatives contribute and subsidize government spending through community initiatives of self-care for their children. Some, skeptics may argue that it is just a "drop in the bucket", and much more needs to be done to assist parents and caregivers. Community efforts can go a long

way to bring dignity and a humane understanding to such initiatives. The lack of training in general, to care for children with special needs hampers their efforts and remains a stumbling block. Without proper training and the necessary knowledge and skills, in certain circumstances, children with special needs could be harmed and can suffer detrimental consequences.

The terms 'children with special needs' and 'children with disabilities' were used interchangeably in this research.

1.1 Orientation of the study

The Sunshine Day Care Centre in Walvis Bay is one of the very few institutions in Namibia that accommodate children with special needs. In this case the Day Care Centre is a special care facility for children with a variety of physical and mental disabilities in the Erongo Region of Namibia. All the children at the Day Care Centre has not previously been assessed and diagnosed for individual disabilities in terms of their mental and physical needs. The Sunshine Day Care Centre accommodates a total population of 105 people with different disabilities from Walvis Bay of whom 55 are aged between one and eighteen years and are cared for there. The Centre for people with special needs was established in 1996, when Social Workers became aware of concerns from parents and caregivers about the need for such a school. At this Centre, parents and caregivers can enroll their children who live with disabilities or impairments and have special needs. Based on the researcher's own observations as a social worker and involvement at the Centre since its inception, and in the capacity as a Board Member at the Centre, the researcher came to the following conclusions: that some parents and caregivers of children with special needs do not always understand the problems of their children and therefore have unrealistic expectations.

Therefore, the explicit purpose of this study is to firstly gain an understanding of the parents and caregivers' perceptions of the special needs of their children. Secondly, by

exploring their understanding and the challenges faced by them, to gauge how they access their own inner coping mechanisms, and finally to determine their knowledge about available resources and their opinion about support groups.

Disabilities are complex, multidimensional, and much a contested discourse. All possible disabilities are clustered under the umbrella of children with special needs. A child with a special need can be defined as a child who has a unique medical or developmental difficulty. Mauro (2015) further classified the term, and advocates that “special needs” is an umbrella underneath which a staggering array of diagnosis can be placed. Special needs are further commonly defined by what a child can’t do-by milestones unmet, activities and experiences denied.

The “parent” of the child is what Malgosa and Malgosa (2007) define as the man and woman responsible for the birth of the child and hence is the biological parents of the child. This definition is buttressed by the Namibian Child Care and Protection Act (2015), it describes a “parent” in relation to a child, meaning a woman or a man in respect of whom parentage has been acknowledged or otherwise established in terms of Chapter 6 of the aforementioned Act. In circumstances where it is not possible for the biological parents to fulfill their responsibility towards the child, a substitute caregiver who can fulfill this responsibility, can stand in for the roles of parents. Caregiver thus means any person other than a parent or guardian, who takes primary responsibility of the day- to-day care of the child.

1.2 Statement of the problem

Having searched numerous databases, on social workers’ perspectives of parents’ and caregivers’ understanding of the care of children with special needs, the researcher can conclude that there is a dearth of empirical research in this regard in the Namibian context. Interestingly, it is noted that studies were found in the context of other African countries. The problem that was identified in this research was the lack of knowledge and understanding of

parents and caregivers of children with special needs. Child welfare programs are always concerned with protecting children and strengthening the ability of parents and caregivers to act in the best interest of the child with special needs.

The question that this study sought to answer was the following:

“What are the perceptions, skills and knowledge of parents and caregivers of children with special needs?”

Four sub questions form the basis for exploring the main question in this study are:

- What do parents and caregivers have to know to correctly handle the special needs child to ensure that the child is always safe?
- How can parents and caregivers become knowledgeable about the diagnoses and prognosis of the special needs child and how it affects caring and handling?
- How can parents and caregivers learn to draw on their inner coping mechanisms when caring for the special needs child?
- How can parents access available resources, services, and information for the special needs child?

McConkey and Chand (2008) assert that special needs occur in every nation and some parents often provide lifelong care to their affected relative. Most research amongst children with special needs has been undertaken in Western, English speaking societies. The study of McConkey and Chand (2008) identified parental stress and pessimism as factors concerning their children’s future. A subsequent concern reported was the fear that their children could get injured, these anxieties imbued parents with a sense of helplessness while a lack of support was also expressed.

The personal health and wellbeing of the parents were another concern in relation to the care and future of their children. Apart from this, they have other family difficulties to manage. Some parents of children with special needs are not prepared to have such a child. The majority of parents do not have any medical aid cover to have pre-birth tests done. Many

of these children with the disability came into this world by surprise. Heller (2013) raises the notion that children with disabilities have considerable special needs. They may be afflicted by physical or mental disorders.

Common issues raised by parents and caregivers relate to the need for parent and caregiver support systems, the lack of opportunities for their children, the impact on marriage, the impact on siblings and fears about the future. Heller (2013) further confirms that support groups can offer powerful emotional support and social connections that can only be extended by people who walked in “their shoes.” Children with severe special needs drain enormous amounts of time, and energy from parents and caregivers. The literature highlights that marriages suffer to a greater degree due to the lack of time for nurturing the marriages and is compounded by the frequent problems around the child. Sibling issues also need attention. She emphasizes the importance to help the family in identifying their negative feelings and to address it effectively through counseling.

Observations transcribed in the process reports of Social Workers (Ministry of Health and Social Service, 1996-2012), revealed that children with special needs dropped out of school because there were very limited or no school facilities for such children in the Namibian educational system. This is an area of concern and a real-life problem in the community. If statistics with regards to the number of special needs children as well as the types and severity of the disability were released by the Ministry of Education, such information could inform the development of appropriate programs by interested stakeholders such as to the parents and caregivers, other related professionals such as nurses, teachers, pastors, and social workers. The focus of such programs would be to equip these children to participate in community life and the job market according to their abilities.

Gutierrez (2009) contends that parents and caregivers of children with special needs have bigger challenges. They often feel alone in their struggle. This research therefore, aims to firstly understand the knowledge and skills of parents and caregivers of children with special

needs at the Sunshine Day Care Centre in Walvis Bay. Secondly, it aims to explore what support might be needed in order to assist them in their daily lives. Thirdly, the perspectives of some employed caregivers of the Centre were also considered concerning their own understanding of the special needs of children.

In Namibia, the National Disability Council Act of 2004 is the regulatory framework that ensures that conditions improve the situation of persons living with disabilities through their functions, powers, and regulations. Enshrined in the National Disability Council Act (2004) is their mission statement that advocates “improving the quality of life through enhancing the dignity, wellbeing, and empowerment of persons with disabilities”. Vulnerable and indigent people constitute the target groups who are: woman with disabilities; children with disabilities; elderly people with disabilities and disabled people living in rural areas. The key areas and rulings of this act highlight awareness raising; prevention, early intervention and health education; treatment, therapeutic aid and orthopedic services; environmental accessibility; access to information and education and sheltered employment; social integration and the environment; social economic and legal protection; training; information statistics and research; family life and personal integrity; organizations for persons with disability and international co-operation.

1.3 Research objectives

The aim of this study is to gain an understanding of parents and caregivers’ perceptions, skills, and knowledge in caring for children with special needs. To achieve this aim, the following objectives were set out:

- To explore the understanding of parents and caregivers on the special needs of their children at the Sunshine Day Care Centre in Walvis Bay.
- To assess the diagnoses of the children with special needs and the coping mechanism of parents and caregivers of children with special needs.

- To explore the challenges of parents and caregivers of children with special needs.
- To identify resources and support systems available to parents and caregivers.

The rationale for this study was to ascertain whether the parents and caregivers fully understood the special needs of their children and if they could care for them according to their needs. The challenges experienced were explored to determine if they understood the support system that could assist them in their functioning. This information is critical to the management of the Centre as well as for the Ministry responsible, line ministries and stakeholders regarding the specific needs of the parents and caregivers towards their children.

1.4 Significance of the study

This study identified possible gaps in knowledge that the parents and caregivers had, and concurred that:

- There was a need for further training for all parents and caregivers irrespective if their children with special needs are at the Centre or not.
- It is foreseen that the research results could contribute to information about the parents and caregivers' understanding of their children, which coping mechanisms they employ and types of challenges experienced.
- The awareness and understanding of resources in the community and how to access these resources.
- The value of a support group as a coping mechanism was explored.
- Parents and caregivers can be empowered through Psycho-education to understand the handling and care of the children and it can streamline referrals to specialists' medical professionals and other resources in the community.
- Cases where urgent intervention was needed could also be identified for the necessary attention.

- Apart from the management of the Sunshine Day Care Centre, other responsible offices could also benefit from the information for future planning.
- Finally, information will be useful for policy development by line ministries for children living with special needs.

1.5 Scope of the Study

The study was for only one district in the Erongo Region with an estimated population of 62 744 people and it did not include the rest of Namibia's population. It did not involve the total inhabitants of Walvis Bay, but only included parents and caregivers of children younger than 18 years, who presented with a disability and who were enrolled at the Sunshine Day Care Centre in Walvis Bay. The researcher made special provision for the level of understanding of the participants who are from different language groups in Namibia. Not everyone was able to understand English, the official language of Namibia. In the briefing session with the participants, the researcher established the need for interpreters, and made the necessary arrangements. The fact that the researcher could only conduct the briefing sessions in two languages established the need for an experienced translator. The interpreter was appointed to enable the researcher to understand those respondents who needed to express themselves in their vernacular.

1.6 Summary

According to the researcher's knowledge, and a thorough search of databases, little research has been conducted to date in the Namibian context from a social worker's perspective of parents and caregivers of children with special needs. A study was found by Haihambo and Lightfoot (2010) on cultural beliefs regarding people with disabilities in Namibia. This current study was necessitated, because of the researcher's involvement over many years with parents and caregivers who were challenged by the severity of their children's special needs,

and who lacked the skills and knowledge and emotional strength to understand their roles as caregivers. Therefore, the decision to undertake this research project was a very personal undertaking. The preceding chapter discussed the orientation of the study, and it explained the significance of the study. The research, further cover the statement of the problem and set out the research objectives and concluded with limitations of the research.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

This chapter reviews the current literature on parenting children with special needs from a Namibian, African, and further afield, from a global perspective. A section of chapter 2 clarifies key concepts used in the study. Thereafter, it situates the special needs child within the Namibian context. The chapter further illuminates the special needs child within the African continent. It concludes the section with a global perspective of the special needs child. This chapter touched on disabilities and human rights issues. The lenses are then turned to the care and handling of the special needs child, the positive aspects in caring for children with special needs, prevention and early intervention, coping mechanisms, available support and resources for parents and caregivers, and lastly a summary concludes the chapter on the relevant literature.

Gona, Mung'ala-Odera, Newton, and Hartley (2011) underscore the lack of research in the African context on care giving for children with special needs. However, the last decade has seen the emergence of several qualitative studies framed within various cultural contexts that examined the parenting and raising of children with special needs.

Service providers and policy makers have a vital role to understand the lived experiences of individual parents or care givers of children with special needs (Green,2007). In the next section, the relevant concepts used in the study and literature review are defined.

2.2 Definition of Concepts

2.2.1 Parent

Melgosa and Melgosa (2007) refer to the biological parents of a child as the man and the woman responsible for the conception of the child. According of the Namibian Child Care and Protection Act (2015), parent in relation to a child means a woman or a man in respect of whom parentage has been acknowledged or otherwise established.

2.2.2 Caregiver

Care-giving is provided by any family member or other informal caregivers. Caregivers that are not related to the child are referred to as informal caregivers. Formal care is provided or subsidized by the government or any organization that provides care in an organized manner to children with special needs, it is sometimes needed to support additional informal care efforts. Fournier, Davies, Patnaik, Elliot, Dreyer, Jasek and Phillips (2009) affirmed that “caregiver” was a common expression used in research literature and it is the most general word that encompasses fully what the term means. The Namibian Child Care and Protection Act (2015) confirmed that “caregiver” means any person, other than a parent or guardian who takes the primary responsibility of the day- to-day care of a child.

2.2.3 Special Needs

“Special needs” is defined by Mauro (2015) as an umbrella term underneath which a staggering array of diagnoses can be wedged. Children with special needs may have minor learning

disabilities or profound cognitive impairment; food allergies or terminal illness; developmental delays that can catch up easily or still be entrenched; occasional panic attacks or serious psychiatric problems. Children with special needs also include children with one or other physical, mental, or intellectual impairment or disability. Thus, the term children with special needs and children with disabilities are used interchangeably in this research.

The definition of “special needs” remains a contested and complex issue. There are different understandings and orientations, and at times moving between definitions. Owusa-Ansch and Mji (2013) contend that some researchers adopted a definition which incorporates elements of the medical, social, developmental, learning, mental and common concerns. The designation is useful for getting needed services, proper goals, and gaining understanding for the child and the distressed family.

2.3 Theoretical framework

It is social workers together with other stakeholders that are mostly responsible for services to parents and caregivers of children with special needs. Social work practice in South Africa and Namibia has been for decades heavily influenced by theories from the United Kingdom and United States. Other influences on how Social work services were rendered hailed from the government’s principles and the history of segregation that also played an influence in the past. The developmental approach to social work practice is the paradigm that emphasized the importance of social and economic development of human beings through empowerment and recognition of their strengths in the helping process. The developmental approach goes hand in hand with the strength-based approach as well as with empowerment. The strength-based approach emphasizes the fact that every person is born with strengths that they bring to the helping process. This requires the social worker and other service providers to recognize these strengths when interacting with the parent and caregiver of the children with special

needs and to make sure that they are enhanced. When focusing on the strengths of the parent and caregiver of the children with special needs, it assist in minimising the weaknesses and leads to the empowerment. The paradigm also takes into consideration the environments that human beings exist in. The culture plays also a role when dealing with the parents and caregivers problematic situations, (Schenck, Mbedzi, Qalinge, Schultz, Sekudu, & Sesoko, 2016).

2.4 The situation of children with the special needs in Namibia

Namibia currently has a total population of 2.48 million people and it is estimated that more than 4% (98 413) of people are living with one or more disability in the country. In terms of age and disability, the largest proportion of persons with disabilities is found in the age groups of 0-4years and 20-24 years. The results of the Erongo region reflects a population of 147801 and the total number of people living with disabilities in the region is 3698, 1710 females and 1988 males. It was ascertained that many people with disabilities are migrating to the Khomas and Erongo regions. The influx to the Khomas region is the highest, with 45% followed by the Erongo region with 33, 1%, these figures have been confirmed by Steytler (2014).

People that live with disabilities and who are older than 18years, qualify to apply for a disability grant from the government, at the time of writing up this research, and if approved, will receive N\$1200 per month per person. The Ministry of Poverty Eradication has the mandate to administer the grants at present on behalf of the government. Parents and caregivers with children under 18years who are disabled can similarly apply for a child maintenance grant from the Ministry of Gender Equality and Child Welfare, the amount payable is N\$250 per month per child if approved.

The number of children living with disabilities aged between 0-4 years who are not enrolled in early childhood development programs have increased from 3359 in 2001 to 5135

in 2011. Organizations in Namibia, for example, The National Federation of People with disabilities in Namibia (NFPDN) advocates for the rights of people living with disabilities and endeavors to improve their circumstances. A community based organization, Children with Language Speech and Hearing challenges (ClaSH), supports children with language, speech, and hearing problems in the capital of Namibia, Windhoek. Through professional programs, training and teaching is offered to children with special needs. In the north-west region of the country Eluwa Special School in Ongwediwa was established as a school for the visually impaired and resort under the auspices of the, the Ministry of Education Arts and Culture. The Chain Welfare Organization in Swakopmund has a Care Centre for special children that accommodate children from the town. The most recent initiative is an upcoming community project in Otjomuise in Windhoek (Namibian Broadcasting Cooperation, NBC, August 2017) a project sponsored by local businesses to provide day care for children with special needs. Welwitschia Private School for children with special needs is situated at Brakwater outside Windhoek (NBC, November 2017). Other community projects in other parts of the country are not known to the researcher.

The requirement to start a community initiative requires registration as set out under the National Welfare Act of 1965 (Act79 of 1965), as amended, by the Ministry of Health and Social Services. The National Disability Council Act No 26 of 2004 is the regulatory body to guiding who desire to work towards the protection and improvement of people living with disabilities in Namibia. The overarching goal of the act is to set up a National Council for Disability to underwrite the functions, powers, and compositions of the Council support.

In the Namibian study on people with disabilities by Haihambo and Lightfoot, (2010) it was revealed that many Namibians believe that disabilities arise from supernatural causes such as witchcraft and improper relationships of family members as causes of disabilities. Such strange cultural beliefs might influence the caring of children with special needs. The findings

further bolster the notion that there is a clear need for counseling and support programs for both parent and caregiver and the child with special needs who has the ability to understand.

2.5 The situation of children with special needs in Africa

Haihambo and Lightfoot's (2010) study found that in Namibia, people in rural areas blame family members of a child with special needs as responsible for the disability of the child. This leads to family members being judged and ostracised and shunned by the community. The author's further purport that parents and caregivers that live in a community with negative cultural beliefs experienced it as guilt and shame, and that this negativity, can influence care giving. They further maintain that it is important to understand the nature of a community, its beliefs, traditions, myths, and history when you are involved in service delivery to parents and caregivers of children with special needs.

Swartz and Watermeyer (2008) discussed the perception of people with special needs throughout history and argue that people with disabilities in certain countries have a history of being viewed as not entirely human. Children and young people with disabilities constitute about 5% of the population of many countries and it appears that the incidence of disabilities among children and adolescents has increased over a period of thirty years. In examining earlier studies and research conducted in Africa on parents and caregivers of children with special needs, they argued these children were often labeled in "pigeon holes". In Uganda and Kenya, perceptions about people with special needs centered on beliefs about being cursed by evil spirits or that it was a punishment from God. As a result, people living with special needs were hidden from the public Gona et al., (2011).

Mpofu and Harley's (2002) study as cited in Haihambo and Lightfoot 2010) reported that in the southern African country Zimbabwe, traditional healers are believed to be more competent in addressing disabilities or mental issues because they could integrate modern and

traditional beliefs. They concluded their work by proposing that within each country, and each cultural group within that country, a unique cultural understanding about disability require appropriate insight and understanding. The goal of such programs should be to increase the inclusion or acceptance of people with disabilities without requiring cultures to change all their beliefs.

2.6 Caring and handling of children with special needs

As mentioned in the definition under “special needs” the diagnoses for children with special needs could be medical and/or developmental and, it concerns mental illness or learning problems or behavioral challenges. It is of outmost importance to know what the correct diagnosis of the child with special needs is, for successful treatment and management thereof. Mauro (2015) outlines the specific categories, under which special needs might be classified, as: medical, behavioral, developmental, learning, and mental disorders. It isn’t undesirable or unmanageable; it just means typical care instructions would need to be modified to meet the medical or developmental needs of the child. The child who is diagnosed with special needs might be chronic, permanent, or transient.

Heller (2013) is of the view that the parent and caregiver will realise at a certain stage that the child commonly can’t do activities by certain accepted milestones compared to what other children can do. In other words, milestones are not achieved. The children may be allergic to certain food, and some activities are then avoided, and experiences are denied. If this hit families, it appears that “special needs” are like a tragic designation. Some parents will always complain that their child have lost their potential. Many other conditions become more troubling with time. Other families will realize that the weakness of their child is sometimes accompanied by strengths, they realize that after the birth of their child they have coping mechanisms that they never knew they had.

According to Nelson and Yadrich (2013) there are different concerns for children with special needs. When there is no confirmed diagnosis or conditions are medically complex, supportive resources can be evasive, and when there are no available resources for the child with special needs, the family caregiver suffers unnecessarily.

Children who suffer certain medical conditions might also be classified as children living with special needs. Mauro (2015) states that these conditions prevent them from going on with their life as “normal” children and include conditions like cancer and heart defects, muscular dystrophy and cystic fibrosis, chronic conditions like asthma and diabetes. Others include congenital conditions like cerebral palsy and dwarfism, and health threats like food allergies and obesity. Children with medical issues may require numerous tests, long hospital stays, expensive equipment, and accommodation for children with special needs. Their families must deal with frequent crises, uncertainty and worry. The Gale Group (2008) claims that, if parents and caregivers and children do not understand the situation, it can cause a great deal of inconvenience and challenges in the family.

Mauro (2015) further conveys that another frequent diagnosis that parents and caregivers must deal with is Attention Deficit Hyperactivity Disorder (ADHD). This is also a medical condition that affects the attention span that drives the individual to focus on important matters. ADHD is a common childhood behavioral disorder, but it can be difficult to diagnose and even harder to understand. Concentration deficits affect children and teens and can continue into adulthood. Another example of an interesting condition is Tourette’s syndrome (T S), which is an inherited disorder of the nervous system, characterized by variable expressions of unwanted movements and noises. It appears in childhood and can be present for longer than a year. TS can be devastating to a parent or caregiver and they may have to be accountable to create and engage situations to respond normally. It might seem that those children who display the above-mentioned type of behaviors should be handled according to the normal type of behavior because they usually appear normal, but these behavior conditions

don't respond to traditional ways of handling a child. The child with these afflictions has no control over their behavior and, the sad part of it is that they don't want to behave like that. Their behavior is also for them an embarrassment. Parents and caregivers require specialized strategies and regular counseling that are tailored to their specific abilities and special needs. If they are not trained or undergo counseling, the question must be asked if they ever will be successful in their tasks.

Mauro (2015) defines developmental disabilities as a diverse group of chronic conditions that are due to mental or physical impairment. Developmental disabilities cause individuals many difficulties in certain areas of their life especially languages, mobility, learning, self-help, and independent living. It can be very devastating and frustrating for a family to deal with. The family must change visions of the future and provide immediate resolutions in caring for, and educating the child. An immense challenge might urge the family to align goals with certain milestones in-between. An example is a diagnosis of Autism and Down syndrome. These children suffer intellectual disabilities and often in bigger cities result into separating the child for professional care into an institution that is tailored to accommodate them. Moreover, Mauro (2015) advised parents and caregivers to be fierce in the handling process and advocates making sure their children receive the service, therapy, schooling, and inclusion they need and deserve.

Mauro (2015) elaborates on children with learning disorders who experienced learning disabilities like dyslexia and central auditory processing disorders. They struggle with school work regardless of their intellectual abilities. They require specialized learning interventions and strategies to meet their potential and avoid self-esteem problems and behavioral difficulties. Parents and caregivers should be sensitive, persistent and goal driven to achieve successes in learning, both with the challenged children and the resources. To identify all these disorders and address them they need specialist information and training.

Mental illness is another disorder and can take many forms just as physical illnesses do. Mental illnesses can also be called psychiatric disorders. All mental illnesses can be treated. Examples are, anxiety disorders where the person feels nervous or worried at times and depression and bipolar disorder. Everyone experiences changes in mood. Sometimes the feelings are energetic, full of ideas, or irritable, and other times the feelings are of sadness. These moods usually don't last long, and the person can go on with their life. Depression and bipolar disorder are two mental illnesses that change the way people feel and make it hard for them to go about their daily routine. Living with a child with mental illness can put family members on an interpretation of mood swings and crises and defiance. The child's problems sneak up on parents and caregivers and they may experience problems of detachment with the child. They must find the right professionals to help them and must make hard decisions about therapy, medications, and hospitalizations if needed. The consequences of missed clues and wrong guesses can be significant according to Mauro (2015).

Despite the individuality and uniqueness of each child and family, there are some common concerns that link parents and caregivers and challenged children together. It includes getting proper care, accommodation, promoting acceptance in the extended family, school and community, plan for an uncertain future and adjusting routines and expectations. Parents and caregivers with children with special needs are often more flexible, compassionate, stubborn, and resilient than other parents and caregivers. Mauro (2015) succinctly referred to it as a person-centered approach with an interest in the aspects of hope in people's life struggles. Parents and caregivers can be dynamic "and in the sphere of greater beings of one's own actions".

2.7 The Parent or Care giver of the child with special needs

McConkey and Chand (2008) believe children with special needs can be found in every nation even though every child with a special need is different, and every family is unique. Therefore, the parent and caregiver can be from any community. The most important understanding of how parents perceive and understand their children is in the words and understanding of the parent and caregivers themselves, (Kisler & McConachie, 2010). The manner in which the parent and caregiver cope with their children with special needs also depends on social handicaps in the community and attitudinal barriers. (How the community reacts towards the parents of the children with special needs). This can lead to unnecessary strain on the parent and caregiver to understand their children. Haihambo and Lightfoot (2010) illuminated these community beliefs in their study, and avers that it can make it difficult for parents and caregivers to support their children to reintegrate into the community, and for children with disabilities to develop a positive self-image.

Nelson and Yadrich (2013) calls the parent and caregivers “family caregivers” and say that they provide invaluable and often life sustaining services to children with special needs. The importance of the family caregivers is often not recognized or often overlooked. Family caregivers are unpaid and often the sole care givers in addition to other children they may have.

Linn (2012) listed general feelings that persons and caregivers of children with special needs may experience:

- Fatigue: Parenting a child with special needs requires more efforts;
- Jealousy: It can be hard to hear about accomplishments of friends’ children;
- Loneliness: It can become very lonely in the life of a parent with a child with special needs;
- Fear: Parents and caregivers may worry that they do not do enough for their child;

- Stop labeling: They must stop referring to the child as “retarded” or not healthy;
- Parents and caregivers are also human beings: They also have a life and they must stop talking and worrying about the child all the time.

It is difficult to describe the situation of the child with special needs to others if you are not affected in one way or another. Parents and caregivers can tell others about the milestones reached in the life of their children. An academic performance is not the only milestone in the life of children with special needs. Much more, for example is the joy of a child, who was born blind and can see after a specific operation.

2.8 Human Rights of People with Special Needs in Namibia

People with special needs were neglected before the independence of Namibia from South Africa, but since 1990, policies have been gazetted to their benefit, although a lot still needs to be done. In 1990, the Namibian Constitution explicitly recognized the inalienable human rights and freedom of all its citizens and by implication included people with disabilities. The National Disability Council Act 26 of 2004 was then enacted by Parliament. The Council has multiple functions and is as follows:

- Monitor the implementation of the National Policy in the manner provided for in this Act;
- Identify provisions in any law which may hinder the implications of the National Policy on Disability and make recommendations in that regard;
- Advise any person responsible for the enforcement of existing legislation which provides for equal opportunities for all people in Namibia on the enforcement of that legislation;
- Comment on proposed legislation which may affect persons with a disability in any manner;

- Consult with persons with disabilities and organizations that render services to persons with disability and takes any other steps in order to obtain necessary information in the implementation of the National Policy on Disability;
- Initiate amendments to the National Policy of Disability to ensure that it takes account of changing circumstances, and
- In general, all necessary steps to improve the situation of persons with disabilities in Namibia.

A disability Unit was set up in 2001, located in the Prime Minister's office where the Namibian government handled issues of disability as a human rights and development issue. It was believed that this approach would move the various sectors of the state and communities to be made accessible and avail services to persons with disability, and the unit was committed to creating equal opportunities to all persons in Namibia. In recent years, this Unit has represented the Government of Namibia in the negotiations on the UN Convention on the Rights of Persons with Disabilities. The primary responsibility for disability issues was transferred in 2005 to the Ministry of Health and Social Services. The Namibian Government signed the United Nations Convention on the Rights of Persons with Disability on 25th April 2007, and ratified the convention including the optional Protocol on the 4 December 2007. In 2016 the responsibility for disability issues was again transferred to the Office of the Prime Minister to improve on services for the rights of people living with disability.

Haihambo and Lightfoot (2010) were of the opinion that cultural myths and beliefs of the Namibians with disability are an important aspect for consideration why implementation of policies thus far was lingering and therefore they advocate for and widespread awareness raising, which goes hand in hand with policy development for people with disability.

The Sector Policy on Inclusive Education in Namibia (2013) aims at building a learning nation through inclusive education and with that they wishes to reach out to all earners because they see education is a fundamental human right and the foundation for a more just society.

Ndengejeho (2006) makes an interesting observation, namely that education is recognized as a right and not as a charity for children with special needs. In Namibia, children living with special needs are afforded their rights as human beings. They have the right to receive care and essentials for childhood development. Their suffering needs to be abolished and their emergency needs must be taken care of. The “fields” are well prepared in terms of policies, but awareness programs and teacher training must be improved before “seeds” are sown. Across Namibia, there are outcries for an inclusive education system or more specialized schools for children with special needs.

After a lengthy investigation into different researchers’ work and years of personal experience of working with people with disabilities, the researcher can concur with the themes in the literature that: people are denied their rights as human beings, for example, access to public places because of architectural barriers or discriminating attitudes. Most public transport is inaccessible to them. Due to this situation, many parents and caregivers of children with special needs lead isolated lives, some are unable to go out on their own, and are therefore prisoners in their own homes. This inability not to be mobile and the lack of resources creates frustration. “They think that they are in the way of others and prefer their own company”.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which has now been considered to be part of International Law, is a significant step towards realizing the rights of people with disabilities. United Nations Convention [UN] (2007) seeks to address discrimination, change perceptions and combat stereotypes and prejudices. It also places an obligation on Governments to ensure that they aid people with disabilities to achieve a state of equality with the citizenry without disabilities of each of their countries. Article 31

of the Convention notes the importance of States to gather research that can inform policy and monitor progress towards the realization of the rights of people with disabilities. People with disabilities need to be able to monitor and evaluate the impact of UNCRPD on their lives and involvement in research will give them the impetus to do so.

There is a strong indication that researchers are attempting to promote the human rights of people with special needs. An evidence action approach is required to ensure that research benefits and makes a difference in the lives of people with special needs. Dissemination of research findings must be targeted to reach the intended people, building knowledge of the rights and responsibilities of people with special needs (Barnes, 2008; [United Nations] 2007). Although there are some outcries for more research, countries, such as Namibia have limited disability research capacity. People are not interested, and the government is experiencing budget constraints to conduct research. Haihambo and Lightfoot's (2010), study suggests that the implementation of disability inclusion policies is more likely to be successful if it built upon positive aspects of cultural dogma about disability.

2.9 Needs of Parents and Caregivers in Caring for a Child with Special Needs

More finely grained qualities and skills are needed to understand how a child's problem translates into parents and caregivers desire for more assistance. Fournier, Davies, Patnaik, Elliot, Dreyer, Jasek and Phillips (2009) guidance parents concerning three issues of importance on how to master the special needs of children.

- Firstly, valid, and reliable measurement of functional impairments may be the most important part of any model attempting to estimate these needs.
- Secondly, behavior problems affect the amount of help a caregiver believes is needed to assist the child.

- Thirdly, knowledge about the severity of the child's special need may be required to be understood by caregivers.

Fournier et al., (2009) assert that it all rests on the professional diagnosis of the child special needs. Apart from diagnosis for their children's condition, parents and caregivers need training on how to handle their children in the correct way. From professional personal observations, many parents and caregivers learn how to cope with their children out of own experience, and as time goes by they learn more and new skills. A positive attitude can help them to adjust to their child's condition. Parents and caregivers draw on their own experiences in the absence of any training or assistance on how to handle their child.

Together with the correct diagnosis, training and guidance is needed to correctly handle the child. It is not only important to train the parents and caregivers, but it has become necessary for awareness raising of the whole family that include the community, service providers as well as the responsible Ministry who has the mandate to take care of people with disability.

Heller (2013) concludes that some parents devote hours to researching available information. They can express common issues such as the need for parents for a support system; they can identify the lack of opportunities for their children; the impact on marriages; the impact on siblings; fears about the future and react and gather information to tackle the challenges.

She further indicates that a support group is also needed and can offer powerful emotional support and social connection that can only be given by people who have been in "their shoes". Sharing of knowledge and the provision of professional support can improve the life of children with special needs and can change the attitude of parents and caregivers especially in resource poor countries (Qayyum, Lasi & Fafique, 2011).

2. 10 Influencing Factors in Parenting and Caring for Children with Special Needs

Many factors affect care giving of children with special needs and the views of different authors are discussed below:

Qayyum et al., (2011) in a study about the perceptions of primary caregivers of children with special needs in two communities from Sindh and Balochistan in Pakistan, reported that there was a need to raise awareness among the families of children with special needs in the community at large. It was also established that home-based community level interviews are needed to reduce social stigma attached to children with special needs. One of the causes of childhood disability in Pakistan was the high incidence of morbidity and mortality which is evident in developing countries, especially in rural areas most possibly due to a lack of facilities such as safe water, sanitation, and health services. Pakistan is a poor country with limited resources and as most of the families have limited incomes, expenditure on the child with special needs creates greater problems for the caregivers. The research shows a strong association between the type of special needs and caregivers' behavior and practices with children with special needs, at home and in the community at large.

In addition, McConkey and Chand (2008) goes further and stated that parents and caregivers often provide lifelong care to their affected relatives. In their study they found parental stress and pessimism were experienced about their children's future. Another concern was the fear that their children will get hurt, while a sense of helplessness and a lack of support were expressed. The personal health and wellbeing of the parents were another concern as is the concern about the future of their children. Due to the lack of resources available to parent and caregivers, they often provide this care to the detriment of their own health and wellbeing. Nelson and Yadrich (2013) reveal that family care of children with special needs tend to report poor health twice as many times as the general population and some believe that care-giving has made their health worse.

They often deal with physical and emotional strain, financial issues, and lack of social support, loss of relationships, marriage strain, stress and feelings of loss and grief for what they dreamed their life and future of their child would be. The poor health not only affects the parent and caregiver, but also affects the ability of the parent and caregiver to adequately care for their children. It also affects the relationship they may have with their partners or significant others. Apart from this, they have other family difficulties to manage. Some parents are not prepared to have such a child and they suffer outstanding closure of their situation. The biggest proportion of parents does not even have medical aid cover for test and medical care afterwards. Many of these children with special needs came into this world because of unplanned pregnancies, (McConkey & Chand, 2008).

Thornburn (2006) found in his study that parents and caregivers are trained specifically for children with disability and their needs. It can reduce the feelings of self-blame, helplessness, and loneliness for parents and caregivers, especially mothers. It can give hope for the future regarding the prognosis of the children with special needs. He highlighted some factors associated with caring for a child with special needs which included: the support system from immediate family members at home; cultural values and beliefs; financial resources; stability for treatment and rehabilitation services for the child with special needs; family values and lifestyle in some cultural groups are the foundation of strength in coping with a child with special needs.

Misunderstandings about the special needs and how to treat the children are the cause of social handicaps and are sometimes due to the negative attitudes that may occur. Certain barriers play a significant role in the shaping of the situation. Other studies note that caring for children with special needs is very time consuming and leaves little time to seek employment and being involved in activities outside the house. Some children's conditions are so severe that the life of the family just revolves around the child with special needs. Lassetler, Mandleco and Roper (2007) iterate that the family becomes so isolated because they prefer to stay at

home because of their child, leading to the child having poor socialization skills. Swartz and Watermeyer (2008) intimate that there is a constant awareness amongst parents and caregivers of what has been lost or was never found. When parents see other children the same age as their child, they are being reminded of where their child should have been now and if not involved in professional aid they continue to fall back in the cycle of blaming and pitting.

The aim must be to assist families of children with special needs to obtain the necessary service and successfully navigate the uncoordinated multi-sector system that is part of the everyday lives of families with children with special needs. There are many sectors in the communities that are not involved in the striving towards improving services for people living with disabilities Mentro (2003).

In families with a child who has a chronic disabling condition, the health and wellbeing of both caregiver and recipient are of importance. Heller (2013) suggests it is important to help families to identify and understand their challenges and negative feelings in order to address it effectively to be successful in their tasks as caregivers.

Education for children with special needs is crucial, both the nature of the problem and the management strategies, but in Namibia with an exclusive education system, management of children with special needs are hampered. Historically, children with special needs have been excluded from accessing mainstream education. A study that underpins this issue is an education study concerned with the special needs of children by Ndengejeho (2006). He argues that the implementation of inclusive education requires a re-think and the re-establishment of teacher training institutions in Namibia in order to get the teaching profession to consider including children with special needs in Namibia in the mainstream education system. Well planned and implemented inclusive education would contribute to the alleviation of inequalities in the education system. A readiness by the whole of Namibia is needed to embrace inclusive education despite differences between the living conditions of people with

special needs and normal people. The study insisted on a revised teacher training programme because the way it is conducted currently leaves much to be desired. It excluded the handling of the child with special needs in the system. Inclusive education needs to start from the “drawing board” in order to be inclusive for children with special needs. Together with teacher training, awareness raising, needs improvement to uncover and address what hinders teaching for children with special needs. To initiate this, the Ministry of Education Arts and Culture should include all the existing personnel and institutions including schools and resource centers to make all the playing fields equal to include the children with special needs. An individualized education program is needed to be developed and the disparity between urban and rural services also needs attention. Generic counseling may be needed for parents, caregivers, and families with children with complex difficulties and a multi- professional input may also be included.

2.11 Challenges in Caring for Children with Special Needs

Nurturing a child with special needs is a major challenge for parents and caregivers, especially those living in communities with limited resources. This includes bearing the financial burden of caring and treatment of the child’s conditions and dealing with limitations and stigma associated with the child with special needs. Fournier et al., (2009) pondered that most parents and caregivers of children with special needs handle them with care, sometimes they are the only ones giving care.

Caregivers information can be used to provide services tailored to the specific care recipient’s needs. It is important to integrate caregiver’s preferences when dealing with children with special needs. Also taking into consideration the limitations and restrictions that vary from house to house it is important to understand the specific child’s special need. This is truer in evaluating needs and planning services for children with special needs and their

families. Parents and caregivers of children with special needs face some of the most difficult challenges for any caregivers.

Qayyum et al., (2011) report in their study that nurturing a child with disabilities is a major challenge for caregivers, especially for those living in resource-poor communities of developing countries. This includes bearing the added financial burden for the treatment of the child's condition. The stigma associated with the disabilities was also identified as a challenge. Another major challenge in their study was that parents and caregivers found it difficult to teach social self-care skills to their children with special needs. They do it themselves to protect the child, but, they cause more damage than good. Together with this, the lack of professional services, healthcare centers, and hospitals, lack of rehabilitation services are also as challenging as well as information and awareness about the availability of health facilities within their communities. Smaller health facilities were available but were not utilized as they were perceived to be non-functional most of the times.

Mauro (2015) realizes that in having personal contact with parents and caregivers of a child with special needs, you realize they have undoubtedly bigger challenges to overcome than ever thought possible. There might be days where they feel alone in their struggle. They might be so busy taking care of their children's need that life somehow may pass by "unnoticed". Their days may be filled with appointments, therapies, and other responsibilities necessary for the wellbeing of the child. Others might, despite the high care given to their children, do not feel much or complain about the burden. They do not always experience the child as a burden. It is more the inability to support the child that is challenging and that creates more stress.

Heller (2013) takes her previous point further and claims that children with disabilities have substantial special needs. The children might have physical or mental disorders. Some are too challenging to treat effectively. Furthermore, she mentions that some parents and

caregivers consult books, websites and national organizations related to the problems that they experience with their children. Not all have access to modern technology; therefore information might not always be available. Children with severe special needs drain enormous amounts of time, energy and some marriages suffer to a greater degree because of lack of time for nurturing the partners. The frequent problems around the child with special needs result that many family matters stay untouched. Sibling issues also need attention. Parents and caregivers might be so busy taking care of the child with special needs that they do not have the opportunity to seek encouragement from those who are in similar situations. At times caring for a child with special needs become so difficult and stressful when parents and caregivers have a lot to do every day to meet the child's needs. They are so busy taking care of the child and others in the family that they don't have time to look after themselves or some forget about their own needs.

Green (2007) is of the view that social isolation and increased emotional distress are attributed to stigma. He further states that positive attitudes amongst parents and caregivers are unrealistic and might arise from a failure to accept their circumstances. Parents and caregivers sometimes deny realizing their exact circumstances. He however realized that such conclusions serve to discourage them to find positive aspects of care and denying them the potential positive consequences. Some parents need constant help and motivation so that they can understand and move forward and truly recognize why some parents and caregivers can experience their children as a blessing.

Some parents must give up their employment or they must employ a caregiver to stand in for them during the day. Some children's disability might be so severe that they will need a fulltime caretaker if the parents are employed fulltime. This can also have its own challenges. They may have that constant worry the child is not well cared for during the day. In many cases some fathers are absent, and mothers are unemployed and do not always have the support of the extended family, (Lassetler, Mandelo, & Roper, 2007).

The person's environment and interactions are also affected and may result in the wellness being compromised. Chiang (2007) and other researchers before him mentioned that physical and attitudinal barriers coupled with stereotypes play a large role in the shaping of public perceptions of persons with disability, for example the cultural beliefs of a community. With regional disparities, the position is much worse in disadvantaged regions where poverty, illiteracy, cultural barriers, and gender discrimination is more widespread.

Marder (2008) reconfirms that poverty, lack of enough resources along with weak social networks are perceived as major hurdles in the care of the child with special needs. Parents and caregivers might be so strangled by their financial constraints that they accept it as normal for their community and do not reach out for help. It is usually communities like these that suffer a lack of resources and will be the last ones to receive support. These communities are usually on the outskirts of the town.

Green (2007) mentions a positive attitude among parents and caregivers arise from a failure to accept their circumstances. They cannot see that their circumstance will never change especially for parents and caregivers having more than one child in a family with special needs. They are in denial about their circumstances. He however, realizes that such attitudes serve to discourage parents and caregivers to find positive aspects of care and denying them the potential positive consequences. In the study carried out in Florida, Green (2007) deliberates that objective burdens (for example lack of services for people living with disabilities) have a greater influence on the "burden of care" than subjective burdens (feelings towards the persons with disability). Being impartial might be one of the most prominent themes that show certain issues which are being experienced regularly. Emotional or subjective challenges such as rejection, stigma, discrimination, isolation, worrying or pity also emerged. Rejection by fathers is a major issue which negatively feeds back into increased financial difficulties.

In their study Mitral, Posarac and Vick (2011) stated that caregivers restricted themselves in activities because of stigma. Many parents and caregivers were further worried about the future of their children because of demands that children with special needs are associated with. They cut down on some other responsibilities, bring about changes in daily activities in trying to make life for the children with special needs easier. Some parents and caregivers would even resign from work as viewed by Schuster, Chang, Elliot, Garfield, Vestal and Klein (2009). Some parents shorten their work hours. It might be a decision to create more personal time to help the child, but it carries more negative emotional and economic consequences. It also implies parents and caregivers may end up spending much more time caring for the child with special health care and forget to communicate outside the house.

2.12 Positive Aspects in Caring for Children with Special needs

King, Zwaigenhaum, King, Baxter, Rosenbaum and Bates (2006) identifies that positives in caring for children with special needs are found in small and simple things. One example reflected in their research of a deeper positive experience by parents and caregivers was respect. Parents and caregivers of “normal” children do not experience the level of respect that caregivers of children with special needs experience

Gutierrez (2009) quotes similar stories told by other parents and caregivers that they may find tips and tools in many aspects that can balance the needs of their own children and may even learn how to cope with their own circumstances. Similar experiences can also serve as a motivation to others. They sometimes just need to bounce ideas from other parents and caregivers who are in a similar situation. It enables adults to learn from others’ experiences and, also offers long-lasting friendship and fellowship.

Informal care by parents and caregivers forms a crucial element of society, taking into consideration the demanding task of providing care to children with special needs. They

perform a job that saves the taxpayer money and decreases pressure on service providers and as well as enabling the family unit to stay together. In examining the care of vulnerable children, Brannen, Mooney and Statham (2009) states that because of life experiences and events in some people's lives, some may feel that they have a "calling" to be responsible and a caregiver for children with special needs.

Linn's (2012) article reports in the Huffington Post what a mother revealed about her child who had serious medical and developmental issues. She pointed out some universal issues. A child with a special need can be both a blessing and a challenge, because the parent doesn't know the heights of victory and joy until noticing the child overcoming the life challenges that hold him or her back. It can move the uninvolved parent to better understanding and being more passionate.

Rehmand Bradley's (2005) research discovered that closer bonds with extended family resulted in more care providers' satisfaction. It was confirmed by Gona et al., (2011) who added that extended family member's support leads to decreased stress. Hastings, Beck, and Hill (2005) identified personal growth, family closeness, increased sensitivity to others, less materialistic attitudes to expand social and political activities and contacts when positive extended family members are involved in the caring process. Kiltay (2005) also argues that there is a joy to be found in caring for people with special needs.

Parents and caregivers might have a clear idea of what they need in the present and future to care for the child. They do not doubt their parenting abilities, (Gona et al, 2011). The image of parents and caregivers of children with special needs might increase in sensitivity and it might be that they earn more respect because of them sacrificing their lives argues Hastings et al., (2005).

The presence of a child with special needs in the family can broaden the horizons for the families' according to Reichman, Comen, and Noorman (2009). It can also increase family

members' awareness of their inner strength, enhance family cohesion, and encourage connections to community groups or religious institutions.

In conclusion, Mauro (2015) mentions that some parents and caregivers might, despite the high care given to their children, not feel much, or complain about the burden, they do not always see their child as a burden, but rather as their responsibility.

2.13 Prevention and early interventions

2.13.1 Antenatal care for pregnant mothers

The Minister of Health and Social Services in Namibia, during the opening of a Waiting Center for pregnant women in the North of the country in March 2016, said that many mothers know at very early stages of pregnancy, when there is something wrong with their unborn child, (Haufiku, 2016). Even earlier, that was recognized by doctors, but many are not taken seriously. This not only frustrates parents and caregivers but wasted valuable time in which mothers and unborn babies could receive services.

Moreover, the importance of the correct antenatal care during pregnancy plays a vital role in the preparation of the family for the child. The United Nations Department of Health and Human Services (2009) revealed that having a healthy pregnancy is one of the best ways to promote a healthy birth. Getting early and regular prenatal care improves the chances of a healthy pregnancy. The care thus begins before pregnancy with a pre-conception care visit to a health care provider. A woman, who suspects that she may be pregnant, should schedule a visit to a health care provider, including a physical examination, weight check and providing a urine sample. The visit will also include discussions about the mothers and infant's health and any questions about the pregnancy. It is here where the multi disciplines can play an important role in the health sector for example HIV counseling and testing information on healthy living

and nutrition. This can help to prevent complications and inform mothers about important steps they can take to protect their infant and ensure a healthy pregnancy. With regular prenatal care woman can reduce the risk of pregnancy complications; following a healthy safe diet; getting regular exercise as recommended by a health care provider; and avoiding exposure to potentially harmful substances such as lead and radiation.

It can help to reduce the risk for problems during pregnancy and to ensure the infants health and development. It also reduces the infants risk for complications. Tobacco smoke and alcohol use during pregnancy have been shown to increase the risk for Sudden Infant Death Syndrome. It can also cause a variety of problems such as abnormal facial features, having a small head, poor coordination, poor memory, intellectual disability, and problems with the heart, the kidneys, or bones. Women must also ensure that the medications they take are safe.

2.13.2 The Correct diagnosis

The correct diagnosis is the first step to be considered in the management of children with special needs. According to the Oxford Dictionary (2016), diagnosis is the identification of the nature of an illness or other problem by examining of the symptoms. A conclusion or decision is reached by the diagnosis.

The diagnosis is about:

1. Medicine, (a) the process of deciding by examination the nature and circumstances of a diseased condition; (b) the decision reached from such an examination.
2. Biology, scientific determination; a description that classifies a group or tax on precisely.
3. A determining or analysis of the cause or nature of a problem or situation.
4. An answer or solution to a problematic situation, (Cottrell &Summers, 2009).

Largely, the literature emphasizes the importance, to understand the child with special needs. Parents and caregivers need to know what the diagnosis is, which will determine the needs and care of their children. The most important fact is that this process satisfies the situation as mentioned by Stolzer (2011). It was further stated that parental perception of the diagnosis must be valued and understood. With no concrete diagnosis, parents and caregivers can be fearsome that people will think their child is “just stupid”. It can only be harder to obtain services for a child without a definitive diagnosis.

When a disability is present without a known etiology, parents and caregivers may feel guilty, because their child is without an identified diagnosis. They may feel that they are the cause of their child’s disability. Parents and caregivers of a child with no known diagnosis have no reference point for their child’s prognosis. They may also have no set treatment program that may be present with other known disabilities. This may also delay the acceptance of the child’s progress. Parents and caregivers of a child where the diagnosis is not known, aren’t able to partake successfully in the kind of social support or have contact with families with similar situations.

Cottrell and Summers (2009) declare that many parents and caregivers never get a specific diagnosis for their children. They only get a diagnosis of delay or global disability for example brain damage, cerebral palsy, mental or physical impairment. Parents would like to know as soon as possible if there are concerns with the condition of their children. It is difficult to obtain an intervention without a diagnosis. The most influential in the diagnosis process is the timeliness of the diagnosis. The sooner they learn about the diagnosis, the more satisfied, they can make an early adjustment and accept the child with the special need. Parents and caregivers want to be told about the diagnosis as soon as possible even if the special needs are uncertain and the prognosis is unknown. Parental reaction to the news is not something to be afraid of and certainly not a reason to delay diagnosis. A prompt diagnosis can only be

beneficial to the family. The earlier the diagnosis of the child with a special need, the more likely parents and caregivers are to be accepting of the results of diagnosis.

Stolzer's (2011) view is that professionals are an important influential factor in the parental perception of the diagnosis process. Professionals are in the difficult positions of sharing undesirable information, so they must try to break the news gently, with sympathy and hope and without being untruthful. There must be a balance between realism and hopefulness. It is not easy to achieve but it is vital for parental understanding and acceptance. After the news is broken, parents and caretakers may have the desire for more information to explain the child's condition. Some may request a written report to have it for further reference. Of importance is that the parent and caregiver must understand the content of the report.

The diagnosis stage is an emotional and difficult time for parent and caregivers. They are often sensitive to the difficult task professionals have. Even if parents must undergo a long diagnostic process they can show a measure of content if they have been treated with care and respect. This only emphasizes the important role professionals play in parental acceptance. They can assist to create a more comfortable time for parents or further add to their pain and helplessness. Stolzer (2011) went further and mentioned that parental perception of the diagnosis may be influenced by less obvious factors such as pre-conceptions, education level, and temperament. They may request advice, re-explanation or with possible follow ups and might request for the involvement of the whole family. Parents may get adequate information but do not understand and, or remember all that was shared. Parental satisfaction with the diagnostic process does not hinge on the actual news, but in how it was given. It is important to allow follow-up visits after the diagnosis was given. Professionals do also not have all the answers, or a set of treatment programs that is needed with all special needs. It is important to understand what the parents and caregivers expect from the diagnosis, to give them clarity about their child's condition. This is the time when they begin to define themselves as a parent and caregiver to the child with special needs and when they begin to construct how their child's

life will be affected by these special needs. A lack of diagnosis or delay or uncertainty in diagnosis, can affect how parents and caregivers cope with and accept the child with special needs. To understand the diagnostic process, all the involved parties must understand the parental belief.

Stolzer (2011) elaborate on the diagnostic process which is important for many reasons. Parents and caregivers may identify this time as a particularly significant time in their child's life. This is the time when they begin to define themselves as parents of a child with special needs, and is also the original time where acceptance begin, although many times only "deep inside."

The authors conclude that societal focus plays a huge role in the acceptance of the diagnosis of the child and the way the treatment will progress. Societal construction is also linked to professional treatment of children with special needs. They have a powerful status in society, much of what they believe, and support becomes ingrained in societal narratives. This affects the parental perception of the diagnosis and acceptance process by affecting the current societal atmosphere as well as professional treatment. With much of the diagnostic process dictated by law, professionals must give parents and caregivers more prominent roles in the diagnostic process. Parent reports are more accurate than professional assessment because they give a more ecologically valued picture of the child with special needs.

2.14 Coping Mechanisms

Heller (2013) described the ideal situation to cope with a child with special needs. She claims it is when the family is regarded as an interactional unit in which all members influence each other. Opposing views, such as divine interventions, sharing of experiences, learning new skills, external support, and the search for a cure were identified by Gona et al., (2011) as coping mechanisms. An interesting coping mechanism that appeared was that parents and

caregiver remain logical when people reject them and stigmatizes them. The experiences of parents and caregivers can be used as best practices in supporting those with fewer experiences and support systems. In support-and-peer groups the experiences should be taken into consideration when grouping them.

Communications and cooperation between service providers and care givers are important so that the needs of children with special needs are met as well as the needs of the parent and caregiver. Through communication, others may learn that they are not alone in their situation. They can learn that there are others sharing similar situations and it can help them accept their own circumstances. Some parent and care givers may cope by bringing in extra assistance from outside like a special caregiver for them to cope with their circumstances and to provide respite services. Although this means an additional financial burden for the family, it might be the best for them to cope. On the other hand, it might be that some parents and caregivers can use this strategy to hide their children at home away from the public eye. It is here where other service providers can play a vital role to guide the parents and caregivers. Some may want to stay close to their children with special needs as a way of being in control of the situation always. Some parents and caregivers may believe that their situation is part of God's plan and they cannot change the situation.

The researcher observed that certain parents and caregivers took their children to local "miracle churches" for prayers with the hope of healing. The latest trend is that they are going as far as to take their children to pastors in other African countries after watching their healings through prayers on television. It might be that although the hope is not for total healing, they rely on the external support (moral and even financial) from their church members. In today's life parents and caregivers should get support from their own churches. Each church should have a benevolence fund so that they can care for the vulnerable people of their church. Emotional support can also come from friends, family, other parents and caregivers, support groups and health care providers. They can rely on social support to cope well with their

circumstances. Some parents and caregivers accept that they do not know everything about their children's conditions and they will easily seek information and assistance related to their children from health care providers, literature or the internet for those who has access.

The opinion of Radzilani-Makatu (2010) is that positive coping strategies keep parents in the present moment and give them chances to actively work towards improving their situation. Although they may not change their situation, they may be able to improve the reception about their situation. Although not all positive coping strategies will work for every person, some may be good and relevant for others. It is well-known by now that attitudes of parents and caregivers and people in the community are shaped and influenced by the prevailing cultural believes. These believes, and practices are found to be strongly associated with religion and socio-economic status.

There must also be some trust between the different professionals and parents and caregivers. A lost in trust in general has its roots in how the professionals treat the situation. Stolzer (2011) argues that professionals tend to predict parental reactions from their own interpretations. Some professionals predict that if a parent and caregiver perceive the news of the diagnosis of their children with special needs well, they will be able to cope with their situation. If they don't cope well, with the news, then they are unhappy with the process. These may be an over-simplification of parental reactions. Circumstances and their reactions and adjustments should be handled individually. Professionals themselves must be aware of their own feelings and coping mechanisms when dealing with the parent and caregivers with the special child. It might be that they feel emotions like that of the parent, although to a much lesser extent. Many parent and caregivers shared heartbroken stories on first hearing the news of the special needs of the child. Intimate moments are revealed, but the professional must still act emphatically. In some instances, professionals and caregivers may find bonds, but still the situation must be kept professionally. The manner in how professionals handle the initial

sensitive stages will also play a role in how parents and caregivers understand their situation or act in the future.

How the parents and caregivers act and cope, depend on the social handicaps in the community with their attitudinal barriers. This can lead to the misunderstanding and unnecessary strain on the parents and caregivers and was all confirmed by Chiang (2007). Parents and caregivers as well as the community should be educated about children with disabilities and special needs. In the Pakistan (2011) study findings indicated a significant impact on the social and emotional well-being of the primary caregivers. The primary caregivers emphasizes that the attitude of people in the community towards their children played a vital role when taking care of their children with special needs. The data also reflected that the sharing of knowledge and provision of professional support could improve the life of their children and it would change the caregiver's attitudes and practices towards these children, especially in resource-poor countries. Studies on parents and caregivers can help to identify the potential areas for an educational intervention for children with special needs which will benefit the caregivers.

Not all coping strategies are good and helpful, and it might influence the psychological well-being of parents and caregivers. For example, if too many outsiders are involved with the child with special needs, not all may handle it well. Some parents and caregivers may prefer to handle it as privately as possible. Such strategies often worsen the stress which may also impact negatively on the parents and caregivers and the parent and caregiver-child relationship. It might be that the parent, especially fathers, distance themselves from their children and some may blame themselves constantly. Proposed strategies to cope are not acceptable for them. Some may also adopt isolation and exclusion of their children from the public and community; they will say they do it to protect their children. In Dunleavy, Lyons, Phelps and Scott's (2010) study on the coping mechanism of parents of children with Autism Disorder, they confirmed parenting these children is highly stressful and challenging. The study indicates that

increasing knowledge of coping on how to deal with these challenges and the formulation of strategies for implementation is needed. The parents reported higher levels of stress when compared to parents that do not have challenges concerning special needs.

2.15 Support and Resources for Parents and Caregivers

Supportive services for family caregivers work best when parents and caregivers' perspective concerning the problems they face, and possible solutions are valued and actively asked for (Fournier et al., 2009). Caregivers information can be used to provide services tailored to the specific care recipients' need. Integrate the caregiver's preferences into the service programs for the distribution of service, especially health services. Understanding caregivers and care recipients' strengths and needs are critical in decision making related to service distribution. The type of special need affects the caregivers' belief of the children's' needs. Children with special needs do not only require their parents and caregivers, but also the assistance available from government services, especially for low-income families and especially for medical related assistance.

Support can be social and physical in nature. Most needs required are usually of material or physical nature, such as financial help and access to suppliers which are both objective. This indicates that the objective burden of care impacts on the parent and caregivers is more than a subjective burden. Parents and caregivers of children with special needs can lose a sense of contact if the health care systems are not available or up to standard. They may disappear in the community and the child may suffer in ignorance. It assumes greater responsibility for the child's well-being (Bailey, Golden, Robert & Ford, 2007).

The above-mentioned was confirmed by Butcher, Wind, and Bouma (2008) when reporting that parents and caregivers raising children with special needs often report insufficient support and feelings of helplessness. A sense of control in the health care system

is important for minimizing challenges experienced by parents and caregivers. Social support need to be associated with better health outcomes for parents and caregivers of children with special health needs. Many have long-term consequences for the parent and caregiver. The latter authors found that having a child with special needs are associated with greater restrictions in activities and daily living; therefore, a support system is important to assist where necessary. Parents and caregivers also need to consider their own health to prevent long-term health complications, thus more important to make use of assistance or support.

Radzilani-Makutu (2010) supports the importance of intervention targeting both mothers and fathers of children with special needs. How parents and caregivers cope in the end depends much on the resources and services available in caring for children with special needs.

Under support and resources for parents and caregivers the ecological systems perspective was applicable in this study. This is widely used in Social Work because it assist social workers in understanding the client systems in totality. In this perspective the client system is viewed as an entity that is constant in interaction with its environment, being influenced and also influenced the environment. The social worker has to make all efforts to understand every system that the client system interact with and the impact the interaction has on the client system. The client system keeps on changing but it is always part of the clients life. The researcher had to explore all the areas that influenced and included the life of the parents and caregivers in the research.

2.16 Summary

In this chapter, a literature study was done with the aim to gain insight into parents and caregivers perceptions of having a child with special needs. The main concepts parent, caregiver and special needs were defined with other related issues described to get a full

understanding of the research topic. The application of human rights of people with special needs was neglected before independence in Namibia, but since 1990 policies have been developed to the benefit of people with disabilities, although more can still be done to improve the situation for parents and caregivers of children with special needs.

The exclusive education system in Namibia was discussed as a contributing factor as well as other influencing factors by researchers and the community on why parents and caregivers of children with special needs may experience challenges to have access to education and training for their children. Although the Namibian government and private initiatives have measures in place to accommodate children with special needs in schools' centers and groups, much more needs to be done.

Due to the financial constraints of the government, no extra expenses can be made currently for new additions. The understanding is, that the government cannot do it all alone. On the other hand, it is extremely difficult for private initiatives and welfare organizations to sustain projects financially, due to the current economic situation in the country. Private donors decreased in numbers because of that, and the corporate world reserves their finances due to the financial instability in the country. The needs of parents and caregivers were further discussed taking into consideration that the circumstances differ from family to family.

Although training to manage children with special needs is of utmost importance, many parents, and caregivers care for their children for the duration of their lifespan, without support, training, and guidance, and still manage successfully.

It is unavoidable for the parent and caregiver to change when the child with special needs becomes part of the family. They have no other way but to accept their children with special needs, although it might take longer for some to come to closure with their situation.

Challenges in parenting and caring for children with special needs were found to be more severe for those living in resource-poor communities. It may include financial burdens,

stigma, and difficulties to teach self-care skills to the children, lack and inadequate professional services, information and awareness about available health services in the communities.

Antenatal care before the birth of the child is important in the prevention of injuries before and after the birth as well as early detection of possible special needs.

A joint multi-disciplinary approach is more beneficial for the parent and caregiver in the managing of their child with special needs. Co-operation between working partners will also ensure more success.

Also, of importance in the parenting and caring of children with special needs is the correct diagnosis for the understanding and correct handling of the children with special needs. It is more challenging to obtain services for a child with special needs without a definitive diagnosis and parents and caregivers may have no reference point for their child's prognosis.

Since the parents and caregivers' circumstances are surrounded by multiple challenges, coping mechanisms are of importance and found in the fact that they must stand firm and loyal despite stigma and negativity that may sometimes surround them.

Lastly but also of importance is the availability of the resources for parents and caregivers in the caring and training for children with special needs. Supportive services work best when parents and caregivers have clear perspectives concerning the problems they face, and it will help to find possible solutions.

CHAPTER 3

RESEARCH METHODS

3.1 Introduction

Humankind constantly tries to improve the world through research, the systematic foundation that we use to obtain new knowledge, and to add to the existing knowledge, and to develop new processes and techniques. In order to conduct research, the researcher must implement research methods. These methods are the strategies, tools and techniques used by the researcher to collect the relevant evidence needed to create theories. These research methods need to be credible, valid, and reliable. This was accomplished by writing a sound methodology which consists of a systematic and theoretical analysis of the above research methods. A method allows the researcher to evaluate and validate the rigor of the study and methods used to obtain the new information Custom Search (2017). It declares research methods constitute only one component of the multi-dimensional research methodology. It is therefore crucial to distinguish between methods and methodology.

The rationale for this study was to ascertain whether the parents and caregivers firstly understood the special needs of their children and if they do their best to help them to develop and if they gave their full support to efforts of the Centre.

In this chapter, the following are discussed after an introduction: research process; research method; research methodology; the research approach; type of research; research design; population; sampling methods; research instruments; semi-structured interview schedule; administration of the research; procedures; sampling; data collection; data analysis; trust worthiness of qualitative research; depth of understanding; subjectivity and

generalizability; confirmability; dependability; research ethics; auditing of the research and a summary.

3.2 Research process

According to Newman (2011) the research process consists of the steps that need to be followed in order to carry out research effectively. It must develop a research problem, carry out an extensive literature review, develop a hypothesis or research question, compose a proper search and sample design, collect data, and conduct an analysis, test the hypothesis, interpret, and discuss data and lastly make conclusions based on the data.

3.3 Research methods

Newman (2011) mentioned further all the techniques, procedures and tools used to collect and analyzed information was the research methods. Research methods are the way in which the researcher obtains the information and find solutions to the research problems.

3.4 Research methodology

The science behind the methods used to gain knowledge, in other words methodology is the study of the methods used and the reasoning behind why a particular method was used. Newman (2011) deliberated it as a way in which to solve the research problems, to explain in which the results were obtained, methods used and the way in which the results were analysed in order to allow the critical evaluation of the research methods. It provides an all-encompassing theoretical and philosophical framework that is used at the beginning of a research project. It furthers explains the functioning and the reasoning behind the research

methods and guide the research process. Methodology seeks consideration in: finding the suitable research method for the chosen problem; discovering the accuracy of the results of a chosen method and ensuring efficiency in the research method.

3.5 Research approach

Newman (2011) explained further the different approaches used in research will help to understand the diverse perspectives encountered in social research studies. The approaches also have an opportunity to make informed choices among alternatives for the type of research to be pursued. There are historically three approaches in research and are: positivist, interpretive and critical social science. Most ongoing social research is based on the first two. Positivism is the oldest and the most widely used approached.

For the purposes of this study, the interpretive paradigm was employed. This approach is concerned with how people interact and get along with each. Newman (2011) mentioned it can be traced from the time of the German sociologist Max Weber (1864-1920). He embraced and felt that personal reasons or motives shape a person's internal feelings and guide decisions". Interpretive social science literally means "making the obscure plain", explained Newman p101 further, (2011). It is also not only the visible external behavior of people that is important. It further discovers what action is needed and what is available and are of crucial importance to the people engaged in this study. The personal circumstances of the participants will have an influence on the way each parent or caregiver handles their child with special needs. Interpretive approaches emphasis voluntary individual free choice and sees people as being able to make conscious choices. Participants were randomly selected and they could choose to take part or not. It is rich in detailed descriptions and participants could describe how they felt.

3.6 Research design

All researchers collect empirical data systematically, and to examine data patterns for better understanding, different approaches can be used. The researcher opted for the qualitative research approach. According to Newman (2011) most qualitative studies start with vague or loosely defined topics, but, and as the study progresses the events turned out holistically (i.e., as a unit in pieces) and individually in their social context. The specific topic emerges slowly during the study, and it may change direction based on new evidence. Flexibility in qualitative research encourages focusing throughout the study. In many qualitative studies the most important issues and most interesting questions become clear only after immersing some data and continuous evaluation. A balance is required otherwise the study will never be completed.

Rubin and Babbie (2011) confirmed and emphasized that qualitative research is not only a data- collecting activity, but also frequently and maybe typically a theory generating activity. A qualitative researcher will seldom approach the task with a precise defined hypothesis to be tested but will try to make sense of the ongoing process that cannot be predicted in advance. It's a process of making observations and revising conclusions.

For this study, the researcher applied the qualitative research approach and gathered in-depth information from parents and caregivers about the caring of their children with special needs in order to understand if they know how to care and handle them. The purpose of this research is to provide interpretive explanatory information, conclusions and recommendations concerning the caring of children with special needs at the Sunshine Day Care Centre in Walvis Bay.

Research design refers to all the technical decisions that were made in the planning of the project. Recordings of what actual people said, examining of written documents, and studying of visual images, observing of specific behavior can all be used. These are specific,

concrete aspects of social life. Through this qualitative data collection information on real life events was obtained. Creswell (2014) indicated that research designs are plans and procedures for research that span the decision from broad assumptions to detailed methods of collection and analysis. The research design that was relevant to this study was the phenomenological paradigm which aims to understand and interpret the meaning that subjects gave to their everyday life (De Vos, Fouche, Strydom & Delport, (2011). According to Rubin and Babbie (2011) qualitative research attempts can go to a deeper meaning of particular human experiences and are intended to generate qualitative data; theoretically richer observations that are not easily reduced to numbers.

3.7 Population

Population is the abstract idea of a large group of many cases from which a researcher draws a sample and to which results from a sample are generalized (Newman, 2011). Creswell (2014) refers to the population as to what presents the entire group of people that was involved, as well as events or topics of interest. It can also be a focus group, a group of people informally “interviewed in a discussion setting that is participating in a qualitative research technique. For this study, the population consisted of parents and caregivers (including employed caregivers at the Centre) of children with special needs from birth to eighteen years enrolled at Sunshine Centre in Walvis Bay. The total number of children enrolled at the Centre with special needs was fifty-five, and the number of caregivers employed by the Centre was fifteen in total.

3. 8 Sampling methods

Sampling is a research technique that is used in social sciences to gather information about a population without having measured the entire population (Newman, 2011). It is a small set of

cases a researcher selects from a large pool and generalizes it to the population. The sample size depended on what you want from the study. When sampling is used, some cases are selected to examine in detail and then using what was learned from them to understand a much larger set of cases. The qualitative research sampling has to establish the circumstances of the study very clearly and directly. De Vos et al., (2011) refer to sampling as a smaller number of a population that is considered as a representation or having characteristics of that of the total population. In this study parents and caregivers of the same circumstances gave replications of their situations. Two sampling techniques are known in research and are non-probability and probability sampling. The first is a sampling technique where the samples are gathered in a process that does not give all the individuals in the population equal chances of being selected. On the other hand, probability sampling is a sampling technique where the samples are gathered in a process that gives all the individuals in the population an equal chance of being selected (Newman, 2011). Probability sampling is the “gold standard” for creating a representative sample. Fifteen parents and caregivers of children with special needs enrolled at the Sunshine Day Care Centre from birth to eighteen years as well as five employed caregivers were selected by means of the purposive sampling method. The researcher developed in-depth analyses from the information obtained from them. In addition, five employed caregivers from the Centre also took part in the sample. The selection criteria were as followed:

- Parents or family caregivers who live together or cared for the child who is enrolled at Sunshine Day Care Centre in Walvis Bay;
- Parents or family caregivers should be above the age of twenty-one years;
- Should be able to communicate in a coherent manner;
- Should be willing to participate.

3.9 Research instruments

A semi-structured interview schedule with open-ended questions was developed by the researcher to obtain comprehensive and comparable data around the area of interest, specifically handling, caring, and coping with children with special needs. According to Creswell, (2014) this research instrument is more advantageous for data collection and it is less time consuming and cost effective. The responses were digitally voice recorded and in shorthand notes for later interpretation and usage, (scribbled notes). The interpretive design seeks evidence that is interwoven to create a unified whole, the concepts, and generalizations are wedded to the context. The researcher thus collected detailed information using a variety of data collection procedures (interviews, audio recordings and observing of the behavior of the respondents as well as the environment).

3.10 Semi-structured interview schedule

Face to face interviews were conducted with parents and care givers and employed caregivers of the Centre. A trustworthy interpreter was at hand to be used for interpretation if the need arises to allow respondents to express themselves to their vernacular. The interpretive social model claims meaningful action through direct observation of people in natural settings is important in order to arrive at understandings and interpretations of how people create and maintain their social world (Newman, 2014). The semi-structured interview schedule with open-ended questions covered the following areas: the relationship of the respondent to the child with special needs; the age of the parent or care giver; the respondents understanding and the diagnosis of the child; coping mechanisms; challenges experienced; knowledge of available resources and if it applied to their needs; resources and the needs of a support systems.

3.11 Administration of the research

Ethical clearance was obtained from the Ethical Clearance Committee of the University of Namibia to conduct this reach. (Appendix H). Permission was requested in advanced from the Management and Board of Directors of the Sunshine Day Care Centre in Walvis Bay to allow for the participation of the employed caregivers of the children to participate in the study. (See Appendix A). The list of children enrolled at the Centre and their particulars were obtained from the administration office at the Centre.

Furthermore, permission for voluntary participation was also obtained from the parents and caregivers as well as the employed caregivers before the actual interviews. Three of the parents and caregivers were interviewed at the Centre, in the boardroom while the others preferred to be interviewed at their homes. Disturbances during the interviews at the Centre occurred, uncontrolled noises of the children living with special needs and other older enrolled people with special needs, could not be controlled. At the homes where the interviews were conducted, noise levels were high due to the setting of informal settlements with small homes and noisy surroundings. There was no one to take care of the children during the interviews. All five employed caregivers of the Centre were interviewed there.

3.12 Procedures

As mentioned, the potential respondents were selected by means of a purposive sampling method. The register of children enrolled at the Centre, as well as the employed caregivers at the Centre were included in the selection. The employed caregivers were engaged through the Centre and for the parents and caregivers home visits were conducted to introduce the research and to lobby for participation. Identified respondents were willing for participation, and indeed

all the participants contacted were willing to participate. Others even enquired why they were not selected. During the collection of data, individual motives according to the interpretive model are crucial to consider even if they are irrational. It carries deep emotions and contains mistakes, beliefs, and prejudice. Ordinary people are engaged in an ongoing process of creating a system of meaning through their interaction. Common sense is a vital source of understanding people (Rubin & Babbie, 2011).

3.13 Data collection

Rubin and Babbie (2011) mentions that data collected from participants must happen in a standardized manner to maximize objectivity. It is important that the researcher prepare him or herself before undertaking direct involvement with the participants. As is true, all research methods begin with a search of the relevant literature filling your knowledge of the subject and learning about what others have said about it. It was also useful to discuss the topic of interest and concerns with someone who is familiar with the topic and the setup. Like in this instance there research was discussed with the coordinator and director of the Centre for the past twenty-one years.

The initial way of contacting the respondents also needed clear planning, formal contact and establishing rapport with them. Although there are many options to make your initial contact with the participant, you should realize that your choice can influence your subsequent observations. The first step is to make direct formal contact with the people you want to study and explain the process and the purpose of the study. Anything the researcher does or not do in this contract, will have an effect of what will be happening or observed in the end. Then the process of qualitative interviewing follows and is always attentive to what is going on. As arranged with the participant the first formal contact, and questions were asked and recorded at this stage. Interviews were entirely open-ended and unstructured.

The design in qualitative interviewing is iterative, that means each time repeating the basic process to each participant. The researcher used the general interview guide with standardized open-ended questions. The interviews were planned in advanced (appointments were made) were flexible, spontaneous; nonetheless the researcher could ask the questions, listened, and made informal notes without interruptions. Highly structured strategies ensured that all respondents were asked the same questions and the interview guide with the issues covered for this study is attached. (Annexure E).

The researcher ensured that the interview data was gathered from each participant on all the relevant questions. Structure eases the researcher's task of organizing and analyzing interview data and helps with the flow of the reading.

3.14 Data analysis

The aim of data analysis is the discovery of patterns among the data patterns that point to theoretical understanding of social life. The researcher applied the Creswell's (2014) approach to analyze the data. These are all specific strategies to analyze data. He presented his approach as a linear, a hierarchical process and he emphasized that these steps are interrelated and does not necessary follow any order. Rubin and Babbie (2011) contend that not all analysis results in counting and sometimes a quantitative assessment of the material is most appropriate with advantages in terms of both time and money.

Steps that were followed in this qualitative data analysis were from Rubin and Rabbie (2011), and are as follows. The data were organized and prepared for analysis, this refers to the transcribing of the interviews and sorting and arranging of the data to get a full picture of the understanding of the parents and caregivers of the special needs of their children. The reading through all the data and listening to the recordings and rethink of what happened during the interviews were repeated a few times. The reactions of the participants and

observations were also considered. The researcher got at this stage a general sense of the information and the overall meaning of the study.

Then the coding of the data follows. This is the process of organizing the data into chunks of information and writing a word that represents a category in the margin. Now the description of the setting or people and categories or themes for analyses can be done. During the coding process the researcher gives detailed descriptions of the setting of people involved as well as description of the categories or themes for analysis. The participants in this study were coded as EC, employed caregiver, P as parent and C as caregiver.

The presentation of the results is called the analysis. This is often done in a narrative passage to convey the findings of the analysis. This may include a detailed discussion of several themes or a discussion of interconnecting themes. Interpretation of the results of the analysis is important because raw material will not make sense.

Then the information was arranged according to themes and sub-themes and described according to what was revealed.

3.15 Trust worthiness of the qualitative data

Like all other research methods, qualitative research has distinctive strengths and weaknesses as described by Rubin and Babbie (2011).

3.15.1 Depth of understanding

Qualitative research is especially effective for studying subtle nuances in attitudes and behavior and for examining social processes over time. The main strength of this method lies in the depth of understanding it permits. Whereas, other research methods may be challenged as

superficial, this is seldom lodged against qualitative research. This research is of greater depth of meaning in describing concepts. Instead of defining concepts, qualitative researchers give detailed illustrations. It was further flexible in that the research design could be modified at any time, as well being cost effective, no expensive equipment or expensive research staff was needed (Rubin & Babbie, 2011). The same questions were used for each participant and each one could describe his situation in his or her own way.

3.15.2 Subjectivity and generalisability

Qualitative research has also weaknesses, although in depth, it is also often very personal. Being qualitative rather than quantitative seldom yields precise statistical statements about a large population. Observations and measurements can produce results that would not necessary be replicated by another independent researcher's. It further often generalized even if a specific subject matter being observed according to Rubin and Babbie (2011).

3.15.3 Conformability

According to Statistics Solution (2017) confirmability is the last criterion of trustworthiness that the qualitative researcher must establish. The criterion has to do with the level of confidence that the researcher's study findings are based on, the participant's narratives and words rather than potential researcher's bias. Conformability is there to verify that the findings are shaped by participants more so than they are shaped by a qualitative researcher.

The researcher was aware of her own biasness during the research and on the outcomes, which could not be separated from what the researcher already was aware of about the phenomenon under study. The researcher was therefore constantly aware of the fact that

personal involvement at the Centre with years of experience should be minimized as to not influence the responses of the participants and skew the outcomes.

3.15.4 Dependability

According to Rubin and Rabbie (2011) dependability in qualitative research can be defined as the stability of data over time and over conditions. Dependability can be compared to reliability in quantitative studies. In other words, dependability is an evaluation of the quality of the integrated process of data collection, data analysis and theory generation. It can be looked at as the researcher's account of the changes built into any setting in addition to change to the researcher's design as learning unfold. Qualitative researchers recognize the reality is socially built and constantly changing conditions and the dependability originates from continuing changing conditions which appears in the setting and the study because of the reality. A dependable study needs to be exact and consistent. Ways to evaluate: (1) Stepwise replication entails several researchers who can be divided into a pair of teams to carry out separate inquiry to view and comparing data in procedure refers to where procedure throughout the analysis can be recoded and the same recode require after a waiting period. (2) Triangulation of the data, is when dependability could be improved by triangulation to make sure that weak points of one approach to data collection are reimbursed using alternative data gathering.

It also refer to the level of consistency of the research findings, which by implication means that the outcome of the study should be consistent if the study were to be repeated with the same participants in the same context. The research project was discussed with the director at the Centre to ensure applicability of the research design and the research plan.

3.15.5 Research ethics

To be engaged in this study, ethical clearance was obtained from the University of Namibia's ethical clearance committee. Similarly, permission was also granted by the management of the Sunshine Day Care Centre to conduct the research from the Centre and to invite parents and caregivers attached to the Centre. Informed consent was also obtained from each participant for participation and each one signed a contract. Participants were also informed that they could at any stage withdraw from participating in the research if they felt uncomfortable and wishes to do so. They were also not in any danger of being harmed because of the set-up of the research. All took part for the duration of the study.

The fact that human beings are the participants in the studies of social sciences brings unique ethical problems to the front which is not relevant in pure clinical laboratory settings of natural sciences and social sciences. Data should never be obtained at the expense of the dignity of human beings. Emotional harm was more difficult to predict and could have negative consequences for the respondents if not noticed by the researcher. In this study participants were informed two weeks in advanced via a letter and invited for an interview at the Sunshine Day Care Centre or at their homes, whichever was most convenient for them. At the first meeting the purpose of the study was explained and further clarification about the study was given to the participants. Permissions were granted by the participants by signing of a contract on a consent form. (See Appendix c). It was made clear that the researcher had no other hidden objectives then stated, and all information was treated with utmost confidentiality. A high standard of ethics was maintained to reflect only true outcomes without any prejudices or partialities. Findings could not be released before the results had been thoroughly examined. It was made clear in the first contact that they could withdraw at any point of the interview if they did not feel comfortable or felt unsafe. In the instance if any

withdrawals occurred, the Centre has a full time social worker who could follow up with counseling if needed.

The following specific ethical issues were taken into consideration during the research (De Vos et al., 2011): Informed consent from the participant; no deception of the participant; no violation of privacy; seeking permission to record the interview; information was of methodologically sound; well designed and executed with care. The transcriptions and the recordings were stored in a safe place and will be erased or shredded, recordings will be deleted as soon as the research is completed

3.16 Auditing of the research

A good report needs to give the reader a good understanding of the study. Auditing is a systematic collection of materials and documents so that independent or external auditors can have comparable conclusions about the data. The purpose is to demonstrate that the different researchers give the same conclusions about the collected data as stated by Streubert and Carpenter (2003). For this study the report was compiled for academic purposes after finalization and successful acceptance and accreditation. The findings will be made available to the stakeholders involved with caring for the children with special needs.

3.17 Summary

This chapter discussed the research methodology employed in this study in order to systematically investigate the research problem by analyzing the logic behind different research methods implemented. The use of a clear methodology must to be reliable, reproducible, and correct in order to produce research that is systematic, logic and replicable. The researcher must have an in-depth knowledge of research methodology in order to be

successful. The researcher applied the qualitative research approach and gathered in-depth information from parents and caregivers and employed caregivers about the special needs of their children enrolled at Sunshine Day Care Centre in Walvis Bay to understand if they know how to handle them. The aim was to determine the extent of the phenomenon.

Even if the strength and limitations of qualitative research were mentioned and discussed in this chapter, it does not have to give the impression that qualitative methods are weaker or stronger than quantitative methods. Which is more appropriate will depend on the aim of the research and the nature of the research questions being answered. The way in which the information and data were collected were explained as well as the trustworthiness of the method used was discussed. Lastly the auditing manner was explained. Chapter 4 will expound on the analyses of the findings.

CHAPTER 4

PRESENTATION AND INTERPRETATION OF RESULTS

4.1 Introduction

The previous chapter focused on the research methodology, and comprised all the technical decisions that has been taken into consideration in the planning and operation of the research project such as the research design, from where the population was drawn; the sample size; the research instruments used; the procedures that were followed and how interviews were conducted with the parents and caregivers and employed caregivers concerning the research, and lastly followed by the data analysis.

The overall aim of the study was to establish the parents and caregivers' perception of the special needs of their children by exploring their understanding and challenges faced, to assess their coping mechanism and their knowledge about available resources and support systems. Similarly, the parent and caregivers' knowledge of the importance of proper diagnosis of their child's condition, and the insight of parents and caregivers on the management of children with such diagnosis with was also examined. Furthermore, the views of parents and caregivers on the value of support groups were also explored. The data collection took place from 28 November 2016 to 24 January 2017.

This chapter will focus on the presentation and interpretation of the results of the research. According to Creswell (2014) qualitative data consist of words and observations. As with all data, analyses and interpretations are enquired to bring order and understanding and requires creativity discipline and a systematic approach. There is no single way, but it depends on the questions answered, the needs of those who will use the information and the responses.

It involved segmenting and taking apart the data according to him “like peeling back the layers of an onion” as well as putting it back together. It goes hand in hand with the collected data, observations that were made and the organizing of the structure of the final report.

The following was be presented: The profile of employed caregivers at the Centre and the reflection of their information; the profile of parents and caregivers (see table 1-2) and the reflection of their information; main themes and sub-themes that emerged from the study followed by discussions of the findings of the present data and the linkage of the literature reviewed and existing literature.

Table 1: Profile of employed caregivers (EC)

EC	Age	Gender	Employment	Education level	Years caring	Place
EC1	44years	Female	Supervisor & Caregiver	Lower secondary	21 years	Kuisebmond
EC2	37 years	Female	Preprimary teacher & caregiver	Lower secondary & Early Childhood	5 years at different post	Narraville
EC3	59 years	Female	Special Class Teacher	Gr.12; Diploma in Special Education	11 years	Town Area
EC4	64 years	Female	Caregiver	Gr. 7; In service training	21years a Caregiver	Kuisebmond

EC5	46 years	Male	Joiner and Caregiver & manage workshop	Gr.10; training at previous work	20years.	Narraville
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Table 1 above on the profile of employed caregivers reflects the particulars of 4 females and 1 male caregiver at the Centre. One resides in the Middle Town, two in Kuisebmond and two in Narraville and presented the main areas of Walvis Bay. The age of the participants ranged from 37 to 64 years. EC2 to 5 are caregivers and trainers while EC1 is a caregiver as well as the supervisor of the other caregivers. The caregivers and trainers have children in their care that they stimulate, guide, and supervise and in addition train them in needlework, gardening carpentry and joinery (those having the ability). EC3 & 5 was trained at their earlier places of work where they were involved in similar training work. The other three were trained through Sunshine Day Care Centre for their specific tasks at the Centre. The Walvis Bay Municipality has a twinning agreement with a city in Norway. One of the agreements is in the form of providing in-service and continuing training and updating and evaluation in the form of refresher courses for the employers and parents and caregivers of Sunshine Day Care Centre. This information was provided by EC3. Three of the employed caregivers, EC1, 4 & 5 are employed for more than twenty years each with children with special needs. The other two, EC2 & 3 have been employed there for five and eleven years respectively. It can be viewed as proof of motivation and passion for their work and children with special needs.

Table2: Profile of parents and caregivers (P/C)

No:	Age & Gender:	Martial Status:	Employment Status:	Educational Level:	Relationship & Age of Child:	Professional Diagnosis & Trained:
C1	46, F	Married	Care giver at Centre	Gr. 7 & in service training	Sister's child, 16 years	Autism; mentally challenged; born HIV/Aids+; yes state doctor; trained
P2	35, F	Unmarried	Care giver at Centre	Gr. 10 & in service training	Own child, 16 years	Mental retardation & dumb; trained
P3	41, F	Unmarried	Care giver at Centre	Lower primary & in service training	Own child, 15 years	Intellectual & skin problem; trained
P4	25, F	Unmarried	Care for baby at home	Gr. 10 & computer training	Own child, 6 years	Hydrocephalus; yes state doctor; trained
C5	57, F	Unmarried	House work at home	Lower primary	Grandchildren, 4 & 5 years	Dumb & paralysed; yes

						state doctor; trained
P6	43, F	Unmarried	Cleaner at private company	Gr. 7	Own child, 5 years	Paralysed & meningitis; trained
C7	20, F	Unmarried	Student	Gr.10, stop training	Sister's child, 16 years	Intellectual problem; yes state doctor; trained
P8	43, F	Unmarried	Factory worker	Gr.9	Own child, 12 years	Paralysed after meningitis; yes state doctor; trained
P9	30, F	Unmarried	Cleaner at the Centre	Gr.2	Own children, 9 & 7 years	Learning disability; yes state doctor; trained
P10	46, M	Estranged	Factory worker	Gr.7	Own child, 10 years	Hunchback; feet problems; trained
P11	54, F	Married	Municipal worker	Gr.10	Own child, 9 years	Mentally retarded; dumb; state doctor assessed

						&referred; trained
P12	32, F	Married	Artisan	Gr.12	Own child, 6 years	Hydrocephalus; yes, state doctor referred to specialist
P13	41, F	Unmarried	Cleaner at the Centre	Special class till 16 years &in-service training	Own child, 4 years	Epileptic; trained
C14	37, F	Unmarried	Factory worker	Gr.4	Grandchild, 4years	Stunted growth; dumb; lame; state doctor; trained
C15	60, F	Married	Housewife	Gr.5	Friend's child, 14 years	Attention (ADHD) state doctor & dumb; trained

In table two it is indicated that the ages of the children range from 4 up to 16 years. One grandmother has two boys of her daughter in her care while another mother has also two daughters with special needs in the Centre. Eleven are the biological children, one the child of a late sister, another one a sister, three grandchildren and one the grandchild of a late friend, total seventeen. Four parents and caregivers are married, one estranged from the husband and ten are unmarried. Five are also employed by the Centre, three as caregivers, two of whom work as cleaners (1 responsible to change the diapers and clean the dining room). All the employers received in-service training at the Centre for their specific tasks and specific needs of the children according to EC1 & 5 except P12. The participants were 14 women and one man. The youngest participant was 20 years old while the eldest was 60 years of age. The education level ranges from: Eight parents and caregivers that were only in primary school, four progressed to Gr. 10, one to Gr.9, one to Gr. 12 and one was in a Special Class at a mainstream school and after 16yrs of age, she was enrolled at Sunshine Day Care Centre. Only one parent underwent training after school. This parent and the father seem to have better employment than the other 13 low paid parents and caregivers. Indications in the table illustrate that eleven parents and caregivers knew what the special needs of their children were although, not all public medical doctors informed them about the precise diagnosis of the child. Some could only give a vague description of the special need. Two were referred by a private medical specialist and only one saw the specialist. Eight of children suffered multiple special needs.

4.2 Presentation and interpretation of the results

4.2.1 Main themes and sub-themes

As previously mentioned the data was analyzed according to Creswell's (2014) categorizing, and presented in a linear, hierarchical process. He referred to it as coding or indexing of the

data. However, categorizing does not involve assigning numerical codes as in quantitative analysis. The researcher must bring meaning to the words before identifying themes or patterns by using ideas, concepts, behavior, inter actions, incidents, terminology, or phrases. The information must be organized into coherent categories that summarized and brought meaning to the text. This was intensive in the present study because the researcher had to read the data over and over, listen to the recording and recall all the observations and read the scribbled notes in order to get all the information together and identify coherent categories for the themes and sub-themes (see table 3).

To come up with themes for the data, the researcher evaluated what the over-all concerns of the participants were. In other words what the subject matter was throughout. So, the ideas that came out in all the interviews were evaluated for the themes. The main ideas involved further different issues of concern and as Creswell (2014) clarified, a study may have several themes with sub-themes. Consequently, the central ideas of the study might be secondary or sub-ordinate themes.

Table 3: Main themes and sub-themes

Theme:	Sub-Theme:
Theme 1: Nature of the special need of child	Sub-theme 1.1: Physical challenged
	Sub-theme 1.2: Mental challenged
	Sub-theme 1.3: Behavior issues
	Sub-theme 1.4: Intellectual issues
Theme 2: Parents and caregivers understanding of the special need of their children	Sub-theme 2.1: Poor understanding of parents/caregiver:

	Sub-theme 2.2: Mental Stability
	Sub-theme 2.3: Acceptance
	Sub-theme 2.4: Ignorance
Theme 3: Coping mechanism:	Sub-theme 3.1: Severity of the special need
	Sub-theme 3.2: Financial constraints
	Sub-theme 3.3: Need for additional assistance over weekends/ Not actually coping
	Sub-theme 3.4: Pretending that they care
	Sub-theme 3.5: Lack of training
	Sub-theme 3.6: Lack of support & resources and understanding
Theme 4: Challenges experienced:	Sub-theme 4.1: Financial burdens
	Sub-theme 4.2: Lack of support from family members and external support
	Sub-theme 4.3: Community un involvement
Theme 5: Sunshine Centre gives meaning in life:	Sub-theme 5.1: Improvement of condition of child
	Sub-theme 5.2: Source of income
Theme 6: Support systems:	Sub-theme 6.1: Importance of training
	Sub-theme 6.2: Support group for parents of

	children with special needs.
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4.3 Discussion of themes and sub-themes

4.3.1 Theme 1: Nature of special needs

Parents and caregivers share a broad perspective on the needs of children, which were grouped into sub-themes as physically, mentally, intellectual, and behavioral challenges of the children with special needs. Respondents further stated that the special needs of the children depend on the professional diagnosis of the child’s condition. The findings revealed that 11 of the parents and caregivers that were interviewed had their children assessed by state doctors and two were further referred to private specialist doctors, but it was clear that not all the parents and caregivers were all well informed about their children’s situation. Some having just a vague idea what might be wrong. The sub-themes will be discussed below.

4.3.2 Sub-themes:

4.3.2.1 Sub-theme1.1: Physical challenges

Physical challenges were observed during the data collection process at the Centre and at the homes. Some children were unable to walk and would remain in one position, while other children moved around by crawling on the floor, unable to walk. Some made uncontrollable noises (they made constant movements and noises and it might be that they are not aware of it and it only stopped when they were asleep) or stayed in the same position: C7 *“My sister is so severely disabled that everyone in the house has to take responsibility to check on her on a regular basis. She cannot even sit up straight. We try to put her up against pillows, but she*

moves gradually down again. Although she has no means of communication, we know that she is aware of things around her, therefore we never leave her alone for too long” Other respondents further revealed that some children suffered multiple health challenges like skin and stomach problems and long-term effects after having been diagnosed with meningitis as babies. Ten parents and caregivers reported that their children suffers more than one special needs. P10 revealed: *“The feet of my daughter are so small she cannot balance herself”*. Other physical problems of children that were reported was that they suffered from, epileptic attacks, hunch backs, complications at birth and some are living with HIV/AIDS. An employed caregiver EC4 reported: *“The children in my care are severely challenged and some are not even aware of anything around them, but despite of all of this, I give individual attention and stimulation to each child on a regular interval during the day. It means I turn each child in a different position to prevent the development of body sores”*. P4 reported; *“My child suffers from hydrocephalus, he is still small, but what if he is older and there is still no cure for him, his head will grow bigger, no I don’t want to think about it now”*. C5 reported: *“I struggle as a single mother all the years with my own children while earning the lowest salaries, now the mother who is also enrolled at the Centre for years for her special problem, got a child that is paralyzed. Here is also a second one but I don’ know what is wrong with him, I just enrolled him also there because he seems slower than his peer group”*.

Fifty percent of the children are wheelchair bound, paralyzed, dumb, cannot hear and some have difficulty in swallowing food. The opinion of EC5 was: *“The children are forgotten in their uncomfortable positions when at home, therefore their constant attention seeking efforts. The older children that can look after themselves under supervision, arrive in and unprepared and unhygienic condition which proves that they were not supervised at home”*.

4.3.2.2 Sub-theme 1.2: Mental challenges

The respondents indicated that some children suffered mental challenges after they had meningitis as babies; similarly, some were born as mentally challenged. The respondents mentioned that some children especially girls' experiences mood swings, are irritable and are constantly sad; while boys are more highly energetic and some experiences anxiety for no clear reason. P 2 mentioned: *"I am also a mother of a sixteen-year-old girl at this Centre. Older children especially girls have mood swings; sometimes they display tantrums for no reason. This is the time that you just have to show love and understanding, and a lot of hugs do wonders"*. C1 reported that her sister's child in her care are not aware of what is going on around him; *"He is in his own world and runs most of the time uncontrollably up and down if he does not go to the Centre during weekends"*. P11 reported: *"My 9-year-old child appears normal but cannot do anything, you will just realize it when you talk to him and he doesn't respond back"*.

4.3.2.3 Sub-theme 1.3 Behavior issues

The employed caregivers at the Centre believed the situation of the children can improve if the parents give their full co-operation in the day care of their children. EC3 was of the opinion that: *"Some parents have no control over their children. After the weekend they are wild, and we have to start with the discipline from the beginning"*. Aspects that were clearly lacking according the employed caregivers were summed up by EC3: *"Lack of good communication; unconditional love, constructive discipline and routine. The discipline and caring are interrupted over weekends after the children come back after three days and longer school holidays"*. The fact that children are constantly running up and down and escaped from the classes usually happened after weekends. EC5 reported: *"They are further constantly looking*

for hugs and attention, it's an indication thereof.” EC2 reported: “Love and acceptance are main ingredients for them and in the information sharing sessions with the parents and caregivers I emphasized proper caring and attention of their children at home”.

4.3.2.4 Sub-theme 1.4: Intellectual challenges

Employed caregivers indicated that some children ended up on the streets as dropouts due to early school leaving and their intellectual impairment problems. EC5 mentioned: *Some mainstream schools have special classes for slow learners up to the age of 16 years. After that age most of them are on the streets or at home just idling. Our aim at the Centre is to take all that early school leavers if we could just get support with the running cost of the Centre and machinery for our protective workshop. Our Urban Constituency councilor assisted the Centre by sourcing assistance / machines for the carpentry workshop. The challenge now attached to that workshop is finances to connect electricity to the workshop”.* It is some of these children that eventually end up at Sunshine Day Care Centre where some parents are caregivers who are concerned about their children’s futures. Although children with intellectual challenges are referred from the mainstream schools to the Centre, some children who had been at the Centre because of intellectual challenges, regained their intellectual ability and rejoined the mainstream school. EC3 reported: *‘We at Sunshine Centre have many success stories. In more than one school in Walvis Bay there are children that were transferred after been prepared by our special class teacher into the mainstream schools. We have a total of 20 success stories since our existence; we even have a boy who was transferred to a school in Swakopmund in the beginning of 2017. Others are transferred from the mainstream schools to the Centre due to no progress (under supervision of an official of the Ministry of Education and Culture). Here we have also multiple successes where children went back to the mainstream school after stimulation from our training and rehabilitation program. The*

children are evaluated by an educational official before reintegration to the mainstream schools:”. There can be many causes for special needs and learning difficulties and there is often an associated problem such as the delay of speech and language and social behavior.

4.3.2.5 Theme 2: Parents and caregivers understanding of the special needs of their children

Some parents and caregivers claimed that they understand the special needs of their children, but due to the unpredictability of the child’s condition, it sometimes leads to exhaustion. Some children suffer multiple special problems and one parent, and one caregiver each have two children in their care with special needs and all four children are enrolled at the Centre. Some public doctors only give a vague description of the child’s condition. P2. Replied: *“The state doctor informed me what is wrong with the child, but I did not understand English, it was only at the Centre that I realized what is wrong with my child, after they took me in for employment and they explained and taught me what to do and involved me in every new thing at the Centre”.*

4.3.2.6 Sub-theme 2.1: Poor understanding

Some parents were given a description and explanation of the special needs affliction from the doctor, but they do not at all understand what it entails. The parents and caregivers all have low-literate abilities, while others are illiterate and have no or poor formal education, just other reached Gr.12 at school. They therefore have limited possibility to do research on their own.

The findings reveal that only one parent took her child to a specialist for a proper diagnosis. It seems she could not accept her child’s condition. She even went as far as and taking her child to a visiting South African specialist. She was looking for a cure for her child,

even from non-medical sources. Fortunately, a parent informed her of the success of the Sunshine Day Care Centre and P12 reported: *“I spent N\$1600 with no success, I was informed by a mother whose child is at the Centre of what it meant for her and her child, and the fee is only N\$100 monthly. I brought him here after I realized there is no cure and that other people who claimed they can help him, is useless. This is now my last hope, I’m so exhausted”*.

4.3.2.7 Sub-theme 2.2: Mental stability of parents

The respondents (EC’s) indicated that the mental stability of parents influenced the parents and caregivers’ understanding of the special needs of their children, EC1 mentioned: *“Three of the biological mothers of children enrolled at the Centre were previously also enrolled at the Centre. They are still challenged because of mental problems. It is only one mother that is taking care of her child by herself, but she could not do it without supervision that she received from the management of the Centre. Her family abandoned her after her mother’s death. For cases like these, the Centre makes special arrangements and accommodates single mothers with children attached to the Centre in a specially sponsored house (from Norway) in Kuisebmond”*. EC13 responded: *“I only took my child for a medical opinion after multiple epileptic attacks. Since he did not have for 3 months, I decided to take him off the medication to see if it will start again. “This mother is a cleaner at the Centre and she commented that: “There is nothing wrong with my child; I will take him to the mainstream school if I have money. ” The caregivers of these children accept it as reality that that the children inherit their special needs from their mothers. C15 reported:” *The boy is just like his mother, she is now in Otjiwarongo and still wonders uncontrollably up and down in the street. If I do not keep strict supervision over him, he will also run in the streets”*.*

4.3.2.8 Sub-theme 2.3: Acceptance without diagnosis

Some parents and caregivers indicated that they accepted their children unconditionally despite the fact that there was no medical diagnosis. P6 accepted her child's special needs from the beginning. She is open minded and said: *"I suffer now but it will eventually get better: "At birth I noticed something was not right with my child and I used ointment and massaged my daughter. It was only two years ago that I was introduced to the Centre and then enrolled my child. I now enjoy the support that was lacking for three years with my child with special needs"*. Like others she accepted her child and take full responsibility. Other parents indicated that they have children that are severely, challenged but they accepted their fate. (PC 4, 5, 6, 7, 8, 9, 11, 14&15): P6 reported: *"I have multiple problems. I am forced to stay away from work on Friday's because I have no one to care for my child at home, but my employer understands. I just must arrange for someone to stand in for me. It is not always possible, but I'm doing it for my child"*. P no 4 reported: *"I cannot work outside the house because my child is not at the Centre full time, when he is dropped off by the bus I must receive him, and Friday's there is no school. So, I'm taking care of a baby at home for an income"*. Some parents and caregivers draw strength from the support they get from Sunshine Day Care Centre.

Another mother left the responsibility to anyone else in the house because she is the main bread winner in the family and is forced to work. After the grandparents died who previously took responsibility, an older child is kept from tertiary education to care for her sister with special needs. C7 replied: *"My mother called me from my studies to come look after my sister, but I want to go back, my education is important"*. Another mother used her son for a year after Gr. 12 to care of his brother when he is not at the Centre. P10 reported: *"I don't know what will I do next year, I cannot prevent my first born for another year from his after-*

school training, his father phoned and said I must make alternative arrangements, so the boy will go for training in 2018, I don't know what I will do"

4.3.2.9 Sub-theme 2. 4: Ignorance

Some parents and caregivers seem to be ignorant and in the process the child did not get the correct care and support. P11 reported: *"My child appears normal and I made plans to move to a rural area where he will be protected after my retirement."* (The child is intellectually challenged and cannot speak). Another mother refused to accept her child has a special need, even though it is obvious. She even refuses to give the child his prescribed epileptic medication because he did not have any fit the last two months, and more critically, she plans to remove him from the prescribed medication. P13 is strongly of the opinion that: *"There is nothing wrong with my child"*. C5 blamed the health system for the special needs of her grandchild who apparently was injured at birth. *"The mother is mentally challenged, and your doctors took too long to assist her during birth"*.

4.3 2.10 Theme 3: Coping mechanism

Most of the respondents complained about the Centre that do not operate on Fridays and school holidays. Some employed caregivers mentioned that some parents send their children untidy and uncared for to school. especially after weekends and school holidays and negligence is clearly visible after long holidays. It is a clear sign that they cannot cope at home. Eleven (P/C1; 2; 3; 5; 6; 7; 8; 9; 10; 14 & 15), acknowledge that they cannot cope due to the severity of their children's special needs. P4 mentioned her child is in still pre-school and she is coping because: *" He is still small and just running around the house and I don't want to think now what will happen if he is older and his problem is not solved by the doctors in Windhoek"*. The

reaction of P10: *"My child is small for her age and cannot walk properly, people stare at her when I took her with me, it hurts but I will not leave her un-attended at home. She also needs to go out"*.

4.3.2.11 Sub-theme 3.1: Severity of the child's special needs

The severity of the special needs of the child plays a role in coping with the children and therefore, more than half of the parents and caregivers indicated that they will never cope again on their own without the support of the Centre.

Apart from two parents and caregivers who each have two children with special needs, other parents and caregivers also mentioned hardship because of multiple challenges. All the parents are recipients of the child maintenance grant of the government amounting to N\$250 monthly stipend. They are all thankful, but with the vulnerable situation of their children, they can do with more support, not only from the government. One employed caregiver expressed his unhappiness about the fact that they who are the neediest people, will never be able to afford specialist medical care for their special needs child. He uttered: *"Will someone never hear our cry for assistance and the opportunity to visit specialist doctors?"*

One caregiver mentioned that she copes at home, but if the home circumstances (personal hygiene) are considered, then the opposite is true. During the home visit the house was untidy and chaotic and everyone was sleeping on arrival.

4.3.2.12 Subtheme 3.2: Financial constraints

Parents and caregivers with children with special needs indicated that they have additional expenses with their children. Most of the children with special needs require to wear diapers, and parents and caregivers mentioned the high cost of it. Some children will remain for the rest of their life on diapers. Respondents further added that certain medication for children with special needs for example for epileptic seizures is expensive and not available at the public hospitals. EC1 mentioned: *“The cost of care at the Centre is N\$ 100 per month, but more than half of the parents cannot afford the fee. Despite the poor payment the children are accepted and treated equally by the employed caregivers. The management is aware of the vulnerable circumstances of some parents”*. She also said that: *“The children with special needs who are going to the Centre on a more regular basis, are more disciplined and are able to follow discipline and routine; “At the Centre the children get three balanced meals per day and at home it might be that they eat only once per day, so it’s important that they attend regularly in order to benefit from the feeding scheme to improve their health. It is also needed to attend every day to keep up with the standards, because at school we teach them about cleanliness, etiquette and good manners, for example they must pray before they eat and say thank you and please when they request something.”*

Half of the parents and caregivers are employed but complained about the extra expenses on Fridays when the Centre does not operate, because they cannot afford to stay away from work on Friday’s when the Centre is not open. Two parents indicated that they have planned with employers to work over weekends to make up the time they take off on Friday’s, but it does not always work out. There is not always someone to stand in for them.

Other parents and caregivers, who might find someone to assist on Fridays, might also not be successful. Respondents mentioned that some children are completely uncontrollable.

C1 said: *“I am sometimes so exhausted, and my mother is old and cannot help any longer. The child is sometime missing for hours and we need to call in the aid of the police”*. P12 responded:

“My child stays behind locked doors when at home, and he can hurt him when not under supervision for twenty-four hours. He eats and drinks anything and destroys whatever he finds.”

4.3.2.13 Sub-theme 3.3: Need for additional assistance over weekends / not actually coping

Parent no. 11’s child was referred by a public doctor to a specialist doctor, but he refused to take his child. The parent said: *“My child will in any case never change, so why waste my money, I am fine with him, he appears normal. It is only when you talk to him that you will realized he has no way of communication”*. One caregiver was unhappy about the fact that she had to give up her tertiary education to look after her sister. C7 stated: *“There must be more aid than Sunshine Centre for our children, my education is important but also the safety of my sister”*. The fact that the children are neglected over weekends and school holidays is another sign that the parents and caregivers cannot cope. The reason behind this is not clear.

4.3.2.14 Pretending that they care

EC2 thought that the parents do not communicate with the children or they don’t even search the bags of the children for the information letters from the school; *“They don’t answer the letters from the school, in general so 50% of the parents and caregivers are guilty here”*. She further mentioned that she usually talks to the parents and caregivers at parent-caregiver meetings. *“I always emphasize at meetings, give your children attention and love at home, and*

take the children with you when you go out, show an interest in your children. Hygiene at home is also important over weekends and during school holidays, we as teachers notice when a child was neglected during school holidays. This is special and vulnerable children, they are already disadvantaged, so we must make sure they get the best available". EC5 replied: "The children in my class can mostly all move around on their own and are teenagers. Although their peers can look after them, these children need parental supervision, and it happens regularly that I must talk to parents and caregivers about the personal hygiene of some children, some cooperate but other show no reaction".

4.3.2.15 Sub-theme 3.4: Lack of training

Respondents mentioned that parents and caregivers received guidance from the Centre on how to handle their children but not all co-operates. There are no other training opportunities in the region. Two parents mentioned that they are fully occupied at work and further in the caring of their children at home, they do not have extra time for other activities. They were all guided at the Centre on the management of the special needs of their children, but they do not have time for regular follow ups at the Centre. They realized that they need extra assistance and training like sign language training and sponsors for diapers and special wheelchairs. They cannot expect that the Centre must provide everything. C1: *"I never realized that I will be able to do such sensitive work, I thought we as a family will suffer alone with our sister's child. There is just some days that I feel I can bring the other family members also to the Centre for training, I feel some days it is too much for me. I'm also an employed caregiver and I am thankful for the training so that I can fulfill my task with these severely disabled children".* P9: *"I never thought in my wildest dreams that I would be able to cope with two disabled daughters. I always tell parents with disabled children at home, come to the Centre you will get training and hope".*

Training is offered to learners, employed caregivers as well parents and caregivers. It improves them intellectually and morally. For most of them it is the only training they were exposed to.

4.3.2.15 Sub-theme 3.5: Lack of support and community resources and lack of understanding

The parents and caregivers do not know about any other service organization that provides services to children with special needs. P3 reaction was: *“Maybe bigger towns have schools for these children, but I am not aware of it”* “P15 was worried about what will happen to the boy when she and her husband will not be there or not strong enough to run after him: *“My husband retired recently, and I have my small business at home to survive. Maybe our own children will look after him. He has been with us since he was two months old. His own mother is just like him, just in the streets and has other children. The grandmother who was my friend died”*.P3 mentioned: *“I work at the Centre and see how management struggles to provide for our children, I know it’s not a government place, so all the companies of Walvis Bay must stand up and assist The Centre who provide for us”*. C5 mentioned: *“No one ever gave me anything apart from the Centre for these two grandchildren that I care for, the government gives \$N250 monthly per child. I use all the money on one child for diapers and medication. The other one luckily does not have so many problems”*.

Three parents’ originally thought their children were bewitched or something in the air influenced them, but their understanding improved later after their involvement at the Centre and on receiving guidance on how to treat them. P12’s reaction on alternatives: *“I spent money on more than one private doctor, even a specialist doctor from South Africa, and even those who claimed they could do something for my child they all failed my child. I’m forced to accept there is nothing on earth for this severely hyperactive child of mine that I must lock up*

for his own safety". EC4 replied: I'm also a mother of a teenage girl, and since she could not attend mainstream school, I used to read a lot about children with special needs. It took me quite some time to accept my child will never be normal although my child appears normal, but she is having a lot of emotional problems, I think I understand her by now. But I will never stop dreaming of my child as a secretary of a big company". EC5 said: "These special children are all just borrowed to the parents and caregivers here on earth, some are just lying and do not know what is going on around them, I wonder some time when I turn them around, what is going on at home. The children in my group are very near to my heart. Although they just lay and look in one direction, there are days that they are not well, I just pray for them for protection. We at the school are just temporarily; they stay the responsibility of the parents irrespective if they know how to handle them or not".

4.3.2.17 Sub-theme 3.7: Sunshine Centre as a reason for my coping

Almost all the parents and caregivers cannot understand their life without Sunshine Day Care Centre. The Centre is the reason why they cope.

P2 mentioned:” *Sunshine Centre gave me hope and light when everything was hopeless and dark around me “*

P1 *“I will tell non-stop about what the Centre can do for a person with a special child, I never knew that I would receive such valuable support for my child, I understand my child now”. “The Centre became my home because the children in my class are my life, and I encourage at each parent and caregiver meeting for co-operation with the Centre because they have a valuable service in exchange for only N\$100 pm, and if they cannot pay, we then accept all, and they come for assistance”, was the response of EC3.*

C1 Found hope for her late sister's child that was without hope before his enrollment at the Centre. *“My sister's child is dumb and has no way of communicating. We found him periodically at the Centre during weekends sitting alone. It means he belongs here, I realize he has some understanding now.”*

The same caregiver proposed to open membership of the existing support group of the Centre to others in the community for children with special needs. The caregiver said: *“A support group is a great idea; we will be able to tell others with children with special needs what Sunshine Centre can offer to them and their children, there is no other place like this in Erongo region”.*

4.3.2.18 Theme 4: Challenges experienced

Lack of support and too many challenges can isolate the family, but for the participants in the study the responsibility for the children are mainly incumbent on the parent and caregiver, the father is absent and uninvolved. The study revealed what P12 described about her family's inability to assist: *“I had family members in the past to help me with my child that is totally uncontrollable, but all of them absconded after one or two weeks, they cannot cope. I tried also the men in my extended family because it's a boy, but with no success. It is so difficult to accept that there is no cure and help for my child. In the processes I neglected my last-born child of 5 years old. That child is also so conditioned to watch over her brother, it's not fair but what can I do. I even brought her to the Centre to be near her brother”*

The parents and caregivers need more than what the Centre can offer and for more than twenty years after its inception, no other community project or church group came forward to assist parents and caregivers with the children with special needs.

4.3.2.19 Sub-theme 4.1: Financial burdens

This aspect was the most critical concern with regards of all the challenges, and confirmed that this vulnerable group of people is hampered by financial constraints. The ideal would have been for these parents and caregivers to be stay at home to take care of their children when not at the Sunshine Day Care Centre. The severity of some of the special needs is such that some children need to be institutionalized to receive full-time care to prevent risk of injuries. Some of the most burning issues are: single motherhood with no support from fathers, lifelong or extended use of diapers, and extra cost for medication for children with special needs. Compounded by all the above parents and caregivers cannot give the rightful attention and supervision to their children, not even to mention the other siblings. C5 response to her financial burden was: *“I do housework in town for most of my life and care for my children alone. Now I’m stranded with two grandchildren with only a government grant of N\$500 per month for both. The first child has severe problems that only money can solve. I do the lowest paid employment in life. The money is not even enough for the diapers and the special medication that the child of 6year’s needs. I am almost at retirement age; will I still have energy and a place to work to care for these children? The biological mother has mental problems and is also enrolled at the Centre. She cannot help in anything and I have no control over her. I am just wondering, when the next pregnancy is coming. I’m having a double burden and I feel sometimes unhappy and heartbroken, but I just have to settle myself and accept my situation. Our life will go on like this with the Centre to support the mother with her two children and me with my struggle at home”*. P5 responded to her condition: *“I was unemployed with 2 daughters with special needs; I was at my last hope when the director at the Centre gave me employment”*.

4.3.2.20 Sub-theme 4.2 Lack support from family members and external support:

Single mothers are the ones that care for their children. It is estimated that a staggering 80% no longer receive the support of extended family members. This problem is worsened by the phenomenon of absent fathers, who have abandoned their responsibilities to provide, financial and emotional support to the mother and children. Four mothers emphasized the significant roles that maternal grandmothers play in their lives. P5 responded to the question about external support; *“I had nothing and no one to turn to. I reported myself to the Director at the Centre and she saved me and my two daughters by offering me employment. I will be thankful for this opportunity forever. Where would I be with my two special needs girls if it was not for the Director at the Sunshine Centre”*. P4: Reported: *“I moved in with my child to a new boyfriend to be able to have accommodation, the biological father contacts me now and then for moral support”*.

4.3.2.21 Sub-theme 4.3: Community un involvement

The community has not yet successfully embraced the idea of upliftment and support to parents and caregivers and their children with special needs. Only one political office reached out to the Centre for support. No church or organization is involved. P2 mentioned: *“Every time that I take my child with me outside the house in the community, people stares at her, it breaks my heart every time. It happens sometimes that the Centre takes the children on outings. I am so thankful for that. There she goes out with the group and the possibility that she will be stared at is not so high. It is also important that she moves outside the house.”* P 2 replied: *“I am employed at the Centre and receives support in the form of food and clothing on a regular basis, I have never received anything from any one for my child and I am not aware of other organizations that help parents with disabled children”*.

4.3.2. 22 Theme 5: Sunshine Centre gives meaning in life

It was clear, and emerged in all the interviews as a main theme, that the Centre plays a significant role in the lives of all children, parents and caregivers and employed caregivers. Only two employed caregivers were employed when the Sunshine Centre was started, now more parents and caregivers work for the Centre, and have job security. EC no 1: *“This was my first employment and I am here since we started in 1996, I am a supervisor of the other employed caregivers and a caregiver of children. I sometimes attend meetings and represent the other caregivers”*. EC: *“I’m here since we opened the Centre, I started as a cleaner, later became a cook, and are now for more than 10 years in charge of the most challenged children enrolled at the Centre”*. P6 replied: *“I am, because of all my problems just at home or at work, I am never active outside these two places, but I go to the Centre for meetings for my child and I gained information that I did not have:”*. P 8: *“My girl is 11years old, she could do nothing for herself for many years, but since she is enrolled at the Centre, the lives of mother and daughter have changed; now maybe, my child will be able to care for herself one day”*.

4.3.2.23 Sub theme 5.1: Improvement of condition of the child

As mentioned previously only one employed caregiver completed Grade 12 and has tertiary qualifications. Under the auspices of Sunshine Day Care Centre all the caregivers are awarded professional certificates after completing their in service training. As an employer, the Centre aims to play a meaningful and supportive role in the lives of its employees and contributes to uplifting their status. EC 4: *“I’m 64 years and is still allowed to work. It helps because of the income I get, and I can still do something for my community”*. EC2 reported: *The experience at the school helps me to care for my own child with disability”*.

All parents and caregivers receive guidance and support that some of them rated as above their expectations. P10 reported: *“The Sunshine Centre is the reason that I cope”*. C 1 responded: *“We as a family gave up hope when my late sister’s child was born HIV-positive. He was hospitalized for two years after his birth, and we thought he won’t make it. He could not communicate in the past, but said his first word two years ago at the age of eleven years. I even noticed a sense of discipline in him although other may not notice it.”*

The Centre introduced a feeding scheme after investigation and findings revealed that some children do not receive enough and well- balanced nutritious meals at home. Three well balanced meals are now served daily. In severe vulnerable cases children also received food parcels to take home. Together with this, useable second-hand clothing is also provided together with free transport to and from the Centre. P1 responded on this: *“I wonder if the managers at the Centre realizes what all their contributions means to us.”*

The Centre also trains the learners and successfully reintegrated some of them in the open job market and mainstream school system after a successful rehabilitation, education, and training process.

A specialized remedial teacher from Norway visits the Centre annually on an exchange agreement program between the municipalities of Walvis Bay and Norway for training, evaluation and technical support. Parent and caregivers, employed caregivers as well as the children receive help from this specialized twinning agreement.

4.3.2.24 Sub-theme 5.2: Source of income

At the Sunshine Day Care Centre EC5 conducted a protective workshop where he trained the youth and early school leavers or children who never attended school in woodwork, joinery, and gardening. He reported: *“We have also other projects where the children received training*

in needlework and others help in the kitchen. In all the projects the children can go into the community after evaluation to be reintegrated in the open job market and work for themselves. We previously placed people out at the local municipality and a local restaurant. Or we periodically sell the items that are made in the different workshops and the learners receive part of the money for the product that they completed”.

After successful reintegration into the economy of the town and in some instances the mainstream education system as discussed previously, these children are able to support their own needs and they can contribute to the household and contribute meaningfully to society

Employed caregivers have been secured of a stable income for many years, to maintain themselves and to be content in their employment. EC3 reported: *“I was in a mainstream school special education stream previously, but could not manage. I applied here for employment and having the benefit of a salary and as well as the relaxed atmosphere, I have been here for 11 years”*. EC1 reported: *“This was my first employment and I’m here for 21 years”*. EC5: *I was in an accident and landed in a wheel chair, and for 20 years this place, and work has been my life”*. EC4 reported: *“I am a pensioner and the extra income helps’*.

4.3.2.25 Theme 6: Support systems

Parents and caregivers mentioned that they were empowered through their involvement at Sunshine Day Centre. They are not alone any longer in their struggle to make life easier for their children with special needs. Respondents also mentioned that although the community does not understand and does not co-operate, they feel less vulnerable, and alone. Other parents know about them and the Centre does its utmost to improve the lives of their children. The current quarterly meetings where employed caregivers discuss the progress and challenges of the children, has the function of a as support group for them. They won’t mind outside parents joining them. Their aim is to promote the valuable service of the Centre.

The Centre has, through the Ministry of Health and Social Services been allocated a full time Social Worker as support for the Centre and parents and caregivers.

4.3.2.26 Subtheme 6.1: Support group for parents and caregivers/Value of Support groups

Support groups have the function of improving communication between parents and the Centre as well as amongst parents and caregivers. A new parent who enrolled his child can find support, acceptance and at the end the long endeavoring closure for their circumstances. It can give hope for the hopeless, help for the helpless and encouragement. P5 responded: *“I am not interested I am just between my work and my house although I realized it could help”*. C7: *“My life is fully occupied I need to study further, although I realized involvement of a support group can inspire and move us towards involvement”*.

The response for a support group for parents and caregivers who has children with special needs was in general positive and encouraging.

P10 responded: *“A support group is a great idea and parents can share ideas”*. P 12 reported: *“I brought my child to Sunshine Day Care Centre after a mother shared with me that her child was enrolled at an ordinary school with no progress, but after two years at the Centre the progress was visible. That time I just spend N\$1600 on specialist care and people who claimed they can help my child. That was the last straw. My child is totally uncontrollable, and I tried all avenues to help him. So, I’m here now”*. P2 responded: *“Since my daughters are enrolled at Sunshine Centre I feel stronger I can do anything that can help my children where my family failed me. So, a support group will be like my family to help me, where I get stuck in my circumstances, they will pick me up”*.

Over-all most parents and caregivers responded positively to the possibility of a support group for parent and caregivers at the Centre. P10 finally responded by stating: *Parents and caregivers can exchange best practices in the handling of their children with special needs and it can help the struggling parent and we can exchange resources.*

4.4 Discussions

This study aimed to establish the parent and caregivers' perceptions of the special needs of their children enrolled at the Sunshine Day Care Centre in Walvis Bay by exploring their understanding, challenges faced, accessing their coping mechanisms, and viewing their knowledge about available resources and a support system. The collected data were analyzed to establish the findings that were presented in this study.

The study identified six themes and 21 sub-themes which were the main areas of the discussions in this chapter. It produced the findings which will be discussed, summarized and concluded. Similarly, parental and caregiver knowledge on the importance of a proper diagnosis or assessment of their children's condition was established. Lastly their views of available resources and the value of a support groups were determined. The present study generated data through the selected sample of five employed caregivers and fifteen parents and caregivers, which was collected from 28 November 2016 to 24 January 2017.

Theme1 focused on the nature of the special needs of the children. The special needs that are referred to in this study fall under one umbrella, the different disabilities are classified by Mauro (2015). Children enrolled at the Sunshine Day Care Centre in Walvis Bay presented with different disabilities. P2, 3 and 13 did not get a professional diagnosis for their children. It was only through their interaction with the Sunshine Day Care Centre that they understood vaguely the description of the special needs of their children. Not all parents and caregivers were able to understand clearly the diagnosis by the public doctors. Eleven were assessed and

some just received a vague description. The lack of proper diagnosis can thus be the reason why parents and caregivers in this study did not fully understand the special needs of their children resulting in not knowing how to handle them accordingly.

P2, 3 and 13 did not get a professional diagnosis for their children. It was only through their interaction with the Sunshine Day Care Centre that they have a vague description of the special needs of their children. Only one mother took her child for specialist medical evaluation and the others could not due to limited finances. P2, 3 and 13 did not get a professional diagnosis for their children. It was only through their interaction with the Sunshine Day Care Centre that they have a vague understanding of the special needs diagnoses of their children. The lack of proper diagnosis can thus be mentioned as the reason why parents and caregivers in this study did not fully understand the special needs of their children in order to know how to handle them accordingly.

Theme 2 represent the parents and caregivers' understanding of the special needs of the children. Some children suffered multiple health disorders which influenced the understanding and handling of the children by the parents and caregivers. Some are physically challenged others mentally challenged. Three mothers of children in the care of caregivers were previously enrolled at the Centre due to mental problems and it seems as if the caregivers view it as a contributing factor to the children's present condition. There are three boys where the parent and caregivers have no control over, due to their tendency to abscond, or who is a danger to himself and must be locked indoors. The employed caregivers accepted all the children unconditionally despite their needs. They claimed that they handle the children with much love and motivated the parents and caregivers during parental meetings to do likewise. The behavior issues experienced at the Centre after weekends and longer school holidays was an indication for the employed caregivers that parents were not coping at home. The children displayed constant attention seeking behavior and was emotionally needy.

Older children enrolled at the Centre came after they were forced to leave the mainstream schools due to their intellectual impairment. The behavior of these children is already established by the time they are enrolled at the Centre. Girls experience mood swings and boys are over energetic and experience anxiety sometimes. The employed caregivers evaluated their physical appearances and personal hygiene after weekends and school holidays and found that there was a lack of control or supervision by parents and caregivers. Some parent and caregivers could due to the unpredictability of their children not fully cope or understand them.

Theme 3 examined coping mechanisms. Lack of understanding might be the reason why some parent and caregivers failed to understand their children or had an extended process to come to closure with their child's circumstances. Most respondents complained about the Centre that does not operate from Fridays to Sundays and school holidays. Others acknowledged they could not cope due to the severity of the children's special needs. Three parents and caregivers put the blame on bewitching as a reason for their child's disability. One parent and a caregiver experienced circumstances as extremely exhausting. Some could not fully cope in their daily lives because they did not know what was wrong with their children. P10 mentioned how she managed before she contacted the Centre: " *My child is of much smaller build as her peers; I always wheeled her around in a baby pram without realizing I prevent her from learning to walk. At the Centre I was advised to leave her on the floor and she learned to walk*".

Theme 4 covered the challenges experienced. The majority of parents cited a lack of financial resources which put constraints on medical aid coverage for medical consultations, especially at the pre-natal stage. Parents and caregivers are therefore reliant on an already burdened public health system. Employed caregiver no 5 was concerned and expressed her views: " *I have one big concern, there is no provision for us disabled persons to visit specialist doctors. Does it mean that I will never be able to have that opportunity? The government can*

at least for us the most vulnerable people in the community, make provision for special medical aid coverage". In the meantime the Ministry of Health and Social Services plans to be more involved in the health of the vulnerable community in general with its planned Universal Health Coverage that will be introduced in the future.

The minimal monthly fee for the caring of the child at the Centre cannot be met by the parents and caregivers. Single parenthood with no support from fathers and other extended family members hampers the progress and development for the child. Five single mothers were unemployed at home and absorbed by the Centre for employment to improve the personal circumstances of the child. Lifelong needs related to the special needs of the child increased the financial constrains for the vulnerable family.

Apart from the Sunshine Centre with highly professional service, support and training, no other organization provides similar care. The parents and care-givers at the Centre are all beneficiaries of the governments maintenance grant.

The value of a support group was emphasized by thirteen of the participants. Apart from the value for them as parents and caregivers they realized there are others in the community with children with special needs that can also benefit of the valuable service of the Centre.

Thornburn (2006) outlines in his study the importance of training for parents and caregivers. EC3 mentioned: *"A parent and caregiver who are not trained to deal with his or her child's special needs can do more harm to the child than good. Children at the Centre that are severely disabled cannot be cared for without specialized training"*.

Theme 5 was covered under the description of what the Centre means to the participants. It was no doubt that the Centre and the assistance received play a significant role in the life of learners, parents and caregivers and employed caregivers. Their lives are enriched, by gaining employment, feeding, clothing, information, technology, professional

care, feeding, protection, and integration and accommodation. Sunshine Day Care Centre is a beacon of hope for those needy, disabled, and indigent members of Walvis Bay in Erongo region.

Theme 6 discussed the support system for parents and caregivers. Through the Centre they meet other stake holders, although the support is not available yet. Support groups benefit the group members emotionally as well as serve as an inspiration to those who feel that society does not care.

In examining the care of children with special needs, Brannen, Mooney and Statham (2009) stated that some people may feel positive in having a child with special needs while others experiences burdens with these children in their lives. Like in the research the severity of the disability, the socioeconomic situation of the family, support systems and the circumstances at home, all impact on cares' experiences (Gona et al. 2011).

CHAPTER 5

CONCLUSION, LIMITATIONS AND RECOMMENDATIONS

5.1. Introduction

The preceding chapter provided interpretations and analyses of the data gathered during the interviews with employed caregivers and parents and caregivers of children enrolled at Sunshine Day Care Centre in Walvis Bay.

This chapter will focus on the conclusions, summary of the objectives and a summary of the present study. Recommendations for practical implications are also provided in this chapter, suggestions and guidance with regards to the future care of children with special needs are discussed. The need for future research was also established.

The aim of this study was to explore the understanding of parents and caregivers of children who have special needs at the Sunshine Day Care Centre in Walvis Bay. The objectives as set out in a previous chapter aim: To assess the coping mechanisms of the parents and care givers; to explore their challenges and to identify if they know what resources and support systems are available; the study further aimed at determining if a support group was needed to assist the parents and caregivers in their functioning; finally, through this study the researcher intended to extend information, recommendations and conclusions concerning the handling of children with special needs that could be valuable to the management to inform policy and procedures and to improve the day to day running of the Centre.

The non-involvement of the community, stakeholders and the prevailing economic recession in the country, and the government's intention to cut cost on all expenditure does not bode well for projects of this nature.

5.2 Conclusion

The study revealed the following after the objectives were met:

5.2.1 Objective: 1. To explore the understanding of parents and care givers on the special needs of their children at the Sunshine Day Care Centre in Walvis Bay.

According to the abovementioned objective most of the parents and caregivers reported they had a vague idea without details of the special needs of their children. Of the reasons were that the communications with regards to the child's diagnosis was in English that was not well understood. Some only really understood their children after involvement at the Sunshine Day Care Centre. Their children were all diagnosed and assessed by the public medical officials. The findings revealed that no parent and caregiver underwent formal training and guidance for the handling and management of their children with special needs before they enrolled their children at Sunshine Daycare Centre. Only after the parents and caregivers reached out and their children were enrolled at the Centre, they received basic training and follow ups and refresher courses through the Centre.

The findings also confirmed that apart from one parent, all the parents and caregivers interviewed, were depended on the public health medical services because they do not have private medical aid or the financial means to access specialist services. Some parents and caregivers acknowledged that they did not fully understand the special needs of their children. This influences the cooperation, progress, rehabilitation, development, and care that the children receive at the Centre. This study also found that during the week Monday to Thursday the employed caregivers stimulate, train, and discipline the children, but after the long weekend at home (Friday to Sunday) and school holidays some of the children become disorientated and not well cared for and the caregivers at the Centre have in some instances to start all over again with the orientation and discipline.

Other parents and caregivers mentioned the severity, unpredictability, and exhaustion of their children's condition as reason why they did not cope.

Some are illiterate or semi-literate which impacts searching for and accessing relevant information of their child's condition.

Others just could not accept the child's situation, and blame non- medical reasons (bewitchment, something in the air) for their children's condition. At the Centre the majority have found closure and more importantly acceptance of their children's condition after enrollment at the Centre.

The mental stability of the parent and caregiver also played a role in the understanding of the child's condition. Although they understood better, it is still difficult to manage. Finally, a number of other parents -caregivers accepted their children unconditionally with all their challenges with or without a medical diagnosis and will the small government grant.

The researcher concluded that not all parents and caregivers fully understand the special needs of their children and not all will always give their full co-operation to the rehabilitation efforts of the Centre.

5.2.2 Objective 2. To assess the diagnosis and coping mechanism of parents and caregivers of children with special needs. In this study, it became evidence that the parents and caregivers do not cope due to the severity of the special needs of the children and because most of them were not properly diagnosed. All of them did not have the support from fathers, extended family members or from friends to aid or stand in for them when the children are not at the Centre. All parents and caregivers appreciated the care and support from the management of the Centre, but they cannot cope when the Centre does not operate during weekends and school holidays. Some mothers are forced to take off from work on Fridays when the children do not go to the Centre. Luckily two employers are empathetic to their circumstances and allow them to take Fridays off and work flexi-hours to make up the time.

Employed caregivers experienced often that some children come un-hygienically and unprepared after weekends and school holidays which showed that parents and caregivers do not cope at home. Others mentioned hardship because of multiple challenges around their children.

Financial difficulty due to low paid employment and lack of financial support are of the main reasons that they do not cope. All parent and caregivers are recipients of the minimal government maintenance grant, which remains insufficient. Some children with special needs having additional expenses because of extended need, (lifelong use of diapers and extra expenses for medication).

According to the employed caregivers the parents and caregivers need regular motivation for cooperation and proper care of their children during information meetings. Not all co-operated and respond to letters from the Centre.

The researcher therefore concludes, that parents and caregivers do not cope well with their children who are present with special needs at home. Generally, all of them expressed their concern about coping without the Sunshine Day Care Centre.

5.2.3 Objective 3. Explored the challenges of parents and caregivers of children with special needs.

Lack of support and too many challenges isolated some families. Everything around the child with special needs revolves around financial constraints. The severity of some of the special needs is that some children need twenty-four-hour care and supervision and some parents need to be with them full time. The vulnerability around poverty is the reason why parent and caregivers are forced to work. The most vulnerable parents and caregivers were absorbed by the Centre and provided with employment to help to improve the children's circumstances. A parent and a caregiver having double burdens, two children each with special needs with increased expenses are enrolled at the Centre. The fathers take no

responsibility and are for all intents and purposes absent, a phenomenon that was discussed in earlier chapters. The unavailability of assistance from the extended family members is a dire need, although they may not be able to contribute financially, they can just be available to help with the supervision when the mother has to go elsewhere.

A full time feeding scheme at the Centre was established after the findings revealed insufficient feeding at home. Free transport to and from the school are also provided in order to ensure that the children attended regularly.

About 50% of parents and caregivers couldn't afford the meager monthly subscription fee, but despite this, all the children are accepted and treated at the Centre.

The study revealed that employed caregivers have a double task concerning the stimulation and discipline of the children. They must fulfill the task towards the children as well as teaching and encouraging the parents to consistently uphold the stimulation process at home. All the employed caregivers complained about lack of commitment from the parents, they leave all the responsibility of the children to them during the week. Some children return neglected and unkempt after the weekend. The employed caregiver must repeat the stimulation process with some children every Monday and after school holidays.

All parents are extremely grateful for the three meals provided per day, the clothing, as well as the periodic food handouts to be taken home from the Centre. It eases the financial strain from them.

All parents and caregivers expressed appreciation for the fact that they could enroll their children at the Centre, some cannot imagine their life without the assistance from the Centre. Some cannot afford the small monthly fee that is payable, and the children are not discriminated against.

The parents and caregivers of children with special needs are of the most vulnerable people in the community and need more support than the Sunshine Day Care Centre can offer to the community.

5.2.4 Objective 4. To identify what resources and support systems are available to parents and caregivers.

The findings revealed that the parents and caregivers do not know about any other services and resources available to them for their children with special needs apart from the public health service and Sunshine Centre.

All parents are in favor of a support group and realize the value that it can have for parents and caregivers who enroll their children at the Centre as well as other parents and caregivers of children with special needs who are not enrolled at the Centre.

5.3 Recommendations

All parents and caregivers requested the government to do more for them concerning the health of their children with special needs. As an example, a medical aid scheme can be put into place that can benefit the poor or at least children with special needs. It can be investigated and implemented so that they can also benefit from the private medical facilities for their children.

They are thankful for the government children's grant, but it is too limited. If the grant cannot be increased, assistance such as the provision of disposable nappies and assistance for the special medication for children with special needs will be of great help.

They mentioned the private business sector as a resource that can be of great help and can support the Sunshine Day Centre in efforts and their striving towards uplifting work of children

with special needs. The twinning agreement and assistance from a city in Sweden through the local municipality can serve as a role model.

The church was also mentioned as an important role player and a resource that is silent in their commitment towards children with special needs.

The following recommendations were made:

5.3.1 It is recommended that the Office of the Deputy President that handles people with disabilities and children with special needs open offices in all the regions so that their services are available to all who need it. It is further recommended that a subsidy be considered from this office to the Sunshine Day Care Centre for each person with disabilities in their care to assist with service delivery.

5.3.2 The Ministry of Health and Social Services has the mandate to care for those who suffer with mental disorders, and the Ministry of Education Arts and Culture is responsible for the provision of education as a basic human right. The Ministry of Gender Equality and Child Welfare has the mandate to look after the welfare of all children under eighteen years of age and is the provider of the government child maintenance grants. It is recommended that the divided social welfare services in Namibia under different ministries being merged under one department to serve the families that include children and people with disabilities. By the merging of resources more programs can be developed and through this powerful government office awareness raising programs and services can be developed to care for the children and people with disabilities.

5.3.3 It is also recommended that the mighty political powers like the Regional Governor's office be used to move the strong economic industries and the corporate world in Erongo

Region, to become involved in the sponsoring and the caring of children with special needs as their social responsibility.

5.3.4 Since the Ministry of Health and Social Services already has a Social Worker attached to the Centre, it is recommended that she budget in the short term for programs at the Centre through her Ministry and provides progress reports of the services offered through the district and regional office to National Level, till an application for a subsidy been finalized through the office of the Prime Minister for the running cost of the Centre. It is further recommended that all the Ministries in family care in the region, work in a combined team with the Management of Sunshine Day Care Centre the Ministry of Health and Social Services and all stakeholders in a rehabilitation and caring program for the whole region.

5.3.5 It is further recommended that all Line Ministries involved in service delivery to persons with disability support the strategies and programs of the National Disability Council Act to bring about the intended goals.

5.3.6 Stakeholder Involvement

The Erongo Region is one of Namibia's economically strong regions especially with regards to the Fishing and Mining Industries. Through these employment opportunities, other industries also developed and established in the region. It is thus recommended that the Board of Management of the Centre investigate in such companies to invest as their social responsibilities when doing awareness raising campaigns with the purpose of more stakeholders' becoming involved in service delivery and sponsoring to persons with disabilities.

5.3.7 Parent and caregivers support

It is finally recommended that parents and caregivers give their full support in the rehabilitation and caring process of their children with special needs.

5.4 Future Research

This study only focused on the opinions of five employed caregiver's and fifteen parents and caregivers involved with children with special needs at the Sunshine Day Care Centre.

Future research is needed that can be extended to the rest of the Erongo Region to support parents and caregivers of children with special needs to make sure they receive the best services and assistance. The services are needed in the remote areas of the Erongo Region to make sure each child with a special need in the Erongo Region has access to and has a fair chance and can receive help from basic human rights as mentioned in the Constitution of Namibia. This research can thus also be extended to other regions to benefit all the people with disabilities in Namibia.

5.5 Summary

The researcher was involved in service delivery to people with disabilities and children with special needs for three decades, a growing trepidation and uneasiness about the poor understanding of parents and caregivers concerning their children's special needs gave rise to the decision to conduct this study. It was therefore concluded that the majority of the parents and caregivers have unrealistic expectations for their children. Another concern was that adequate support and uplifting initiatives for the Sunshine Day Care Centre has not been

forthcoming from the society. Stakeholders who have the mandate to care for children with special needs are sluggish about their responsibility. The most common aspects from the research were:

Parents and caregivers acknowledged services, support and care provided through the Centre and experienced employed caregivers as competent who enrich and improve their children's life.

To create a positive well-planned and meaningful rehabilitation process, so that employed caregivers not only criticize the efforts of parents and caregivers. Acknowledgements of efforts of parents and caregivers can also motivate them and move them to improvement and progress. Even small efforts and initiatives are worthy of acknowledgement. This was totally absent in the handling of the parents and caregivers by the employed caregivers. Expectations, encouragement and support to parents and caregivers go hand in hand.

It can promote existential hope in the present situation of the family and improvement in the future. No one can really understand the shock and feeling a parent and caregivers experiences in having a child with special needs.

They are plunged into an unknown world and have a struggle to navigate through this world without direction. It was more confusing for these parents and caregivers because they were denied support by the fathers, extended family members, the community and other resources in the community.

Despite major challenges, and originally no training to care for their children, parents and caregivers of children with special needs draw strength from small steps of progress and improvements to master their everyday activities, to be hopeful and to construct a meaningful life despite serious and challenging obstacles. Service providers should draw on these insights

to enhance the care support and the parents and care givers need and to help them to set realistic and achievable goals.

All parents and caregivers experienced positive feelings about their children with special needs at one or other stage, despite some who experienced severe difficulties due to multiple children with special needs in their care and the severity of the disability. Parents and caregivers cope in life with so little, no network and support that is usually provided by the state in many other developed countries.

Parents and caregivers are depended on the support and services from the Centre. The study discovered and concluded that parents and caregivers originally did not understand the special needs of their children but after they enrolled their children at Sunshine Day Care Centre their understanding increased. Despite this improvement, training, and guidance by the Centre, they do not cope with the special needs of their children in instances when the disability is severe, challenges too much and if there is a lack of a support system.

The findings of the study also revealed that line ministries are not involved in the implementation of their mandates towards children with special needs and other resources are absent.

The researcher is of the opinion that the time has come that each line Ministry has to revive and renew their responsibility towards children with special needs and that they must invest in collective efforts for the provision of services.

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APPENDIX A:

Barbara Van.Rooyen
P.O box 8137
Narrawille
Walvis Bay
1 September 2015

The Director
Walvis Bay Child and Family Center
P.O. Box 2481
Walvis Bay

Dear Mrs. E. Murangi

**PERMISSION TO CONDUCT RESEARCH AT SUNSHINE DAY CARE CENTRE
WITH PARENTS AND CAREGIVERS OF LEARNERS YOUGHHER THAN 18 YEARS**

I am a master student in Social Work at the University of Namibia and wish to do my research at Sunshine Day Care Centre to determine if the parents and care givers at the Centre fully understand the special needs of their children and if they know how to handle them. I further wish to determine with the research if a support group is needed for them.

I request your good office for permission to do my research at your Centre.

The following are my contact numbers: Tel nr. 064-4106070 (w), fax nr. 064-4106002 and cell nr. 0812439605.

Your urgent response will be appreciated.


Barbara Van Rooyen

Student nt.201090481

APPENDIX B:



P.O. Box 2481 – Walvis Bay – Namibia
Tel: (064) 203534
(064)203368
17 October 2016

North Hospital – 11th Street – Walvis Bay
e-mail: wbctc@iafrica.com.na
fax: (064) 203534

Incorporated Association Not for Gain
(Reg. No. 21/95/231)
(WO 165)

B van Rooyen

P.O. Box 8137

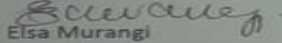
Walvis Bay



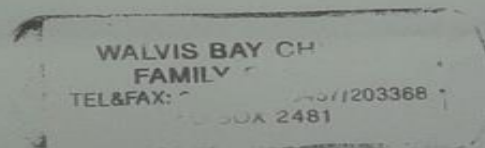
Permission are hereby given to conduct research with parent and caregivers. It is with great pleasure that we advice that your input will help to be able to gain knowledge and understanding on how to deal with children with special needs. Therefore you are granted permission to conduct the research at the centre.

We trust that you will find this in order.

Regards,


Elsa Murangi

Co – ordinator Child and Family Centre



APPENDIX C:

Barbara Van Rooyen
P. O Box 8137
Narraville
Walvis Bay
7 September 2016

.....

.....

.....

Dear Parent/ Care giver

**RESEARCH TO ESTABLISH IF PARENTS AND CAREGIVERS UNDERSTAND
THE SPECIAL NEEDS OF THEIR CHILDREN ENROLLED AT SUNSHINE DAY
CARE CENTRE**

The writer of this letter is a Masters Student in Social Work at the University of Namibia. (Student nr. 201090481). She is planning to do research to establish if the parents and caregivers of children with special needs fully understand their children, and if they have the need for a support group.

You are hereby friendly requested for your participation in the research. The outcome of this research will help in the planning and delivery of further services at the Centre and in the community. In the long run it can benefit other children living with special needs.

You are therefore invited for further clarification and an interview at the Centre on.....

Thank you for your support and participation in advance.

Barbara Van Rooyen

APPENDIX D:

Informed Consent for Participants

Introduction:

My name is Barbara Van Rooyen student nr. 201090481. I am a Masters student Social Work at the University of Namibia.

Thank you for your willingness to take part in this research. The purpose of this research is to find out if the parents and caregivers of children with special needs understand the needs of their children and to establish what their challenges are and if they have a need for a support group.

I assure you that you will remain anonymous and no record of your responses will be kept for any other purpose than the research in the special needs of children.

Instructions:

There are no right or wrong answers to questions contained in this interview. Please feel free to respond to interview questions.

To guarantee confidentiality your responses will be handled anonymously, that is measures will be taken to ensure that you cannot be linked to the answers that you provided to the questions.

You are also not required to give your name to the interviewer, instead numbers will be used.

Please answer all questions to the best of your ability and do not discuss the content of this interview with others. Your personal opinion is highly valued in this interview.

You will receive no direct benefit for participation in this study. However, your participation may help parents and care givers to better understand children with special needs.

Any information about you during this study will be treated strictly confidential to the full extent permitted by applicable research ethics.

Permission:

I agree to participate in the study as describe above.

Yes or No.

I agree to have the interview audio recorded.

Yes or No.

Taking part in this study is voluntary where I am at liberty to withdraw at any point in time.

APPENDIX E:

Interview schedule

Questions for employed caregivers at the Sunshine Day Care Centre in Walvis Bay.

What do you think about the care and attention that the parents and caregivers provide to their children who are enrolled at the Centre?

Do parents and caregivers know how to handle their children with special needs, explain your answer?

Give your opinion about the cooperation and support of parents and care givers to efforts by the Centre.

What is your comment with regard to this type of resources and services in this town, the region and Namibia?

In your opinion is this resource helpful for the parents and caregivers?

What training or guidance did you receive in the handling of children with special needs?

What do you think about a support group for parents and care givers of children who live with special needs?

In your opinion are there any other information that is important for parents and caregivers to understand their children and to assist with the caring and handling.

APPENDIX F:

Interview schedule

Questions for parents and care givers of children younger than 18 years enrolled at Sunshine Day Care Centre in Walvis Bay.

How are you related to the child?

What is your marital status?

Is the child male or female and how old is the child?

How long are you caring for the child?

What do you understand with the term "a child who live with a special need"

Do you think your child can also be called a child who lives with a special need, and can you explain your answer?

Are you coping with the caring and handling of your child?

What training or guidance did you receive in the caring and handling of your child?

Who offered the training and was it helpful?

Do you have full control over the situation of your child or not, and can you explain your answer?

What are the future dreams you have for your child?

What are the fears about the future for your child?

What role do your other family members play in the handling of the needs of your child?

What drives you to go on in life?

What are the types of services provided by the Centre?

How do you feel about the services offered by the Centre?

What are the challenges you have with your child and how do you handle it?

Explore the type of resources available in this town, the region and in Namibia?

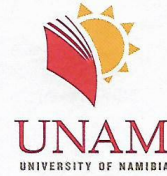
In your opinion, are the resources helpful?

What do you think about a support group for parents and caregivers of children who live with special needs?

Do you have any additional information that you think that need to be taken into consideration in the caring and understanding of children who live with special needs?

APPENDIX G:

University of Namibia, Private Bag 13301, Windhoek, Namibia
340 Mandume Ndemufayo Avenue, Pioneers Park
☎ +264 61 206 3111; URL: <http://www.unam.edu.na>



RESEARCH PERMISSION LETTER

Student Name: Barbara van Rooyen

Student number: 2010901481

Programme: MA Social Work


Approved research title: perceptions of caregivers on the special needs of children at the Sunshine Day Care Centre in Walvis bay

TO WHOM IT MAY CONCERN

I hereby confirm that the above mentioned student is registered at the University of Namibia for the programme indicated. The proposed study met all the requirements as stipulated in the University guidelines and has been approved by the relevant committees.

The proposal adheres to ethical principles as per attached Ethical Clearance Certificate. Permission is hereby granted to carry out the research as described in the approved proposal.

Best Regards



Dr M. Hedimbi
Director: Centre for Postgraduate Studies
Tel: +264 61 2063275
E-mail: directorpgs@unam.na

12 June 17

Date

APPENDIX H:



ETHICAL CLEARANCE CERTIFICATE

Ethical Clearance Reference Number: FHSS /214/2017

Date: 6 June, 2017

This Ethical Clearance Certificate is issued by the University of Namibia Research Ethics Committee (UREC) in accordance with the University of Namibia's Research Ethics Policy and Guidelines. Ethical approval is given in respect of undertakings contained in the Research Project outlined below. This Certificate is issued on the recommendations of the ethical evaluation done by the Faculty/Centre/Campus Research & Publications Committee sitting with the Postgraduate Studies Committee.

Title of Project: Perceptions Of Parents And Caregivers On The Special Needs Of Children At The Sunshine Day Care Centre In Walvisbay

Nature/Level of Project: Masters

Researcher: Barbara Van Rooyen

Student Number: 201090481

Faculty: Faculty of Humanities and Social Sciences

Supervisor: Dr. J. Ananias

Take note of the following:

- (a) Any significant changes in the conditions or undertakings outlined in the approved Proposal must be communicated to the UREC. An application to make amendments may be necessary.
- (b) Any breaches of ethical undertakings or practices that have an impact on ethical conduct of the research must be reported to the UREC.
- (c) The Principal Researcher must report issues of ethical compliance to the UREC (through the Chairperson of the Faculty/Centre/Campus Research & Publications Committee) at the end of the Project or as may be requested by UREC.
- (d) The UREC retains the right to:
 - (i) Withdraw or amend this Ethical Clearance if any unethical practices (as outlined in the Research Ethics Policy) have been detected or suspected,
 - (ii) Request for an ethical compliance report at any point during the course of the research.

UREC wishes you the best in your research.

Prof. P. Odonkor: UREC Chairperson

A handwritten signature in black ink, appearing to be 'P. Odonkor', written over a horizontal line.

Ms. P. Claassen: UREC Secretary

A handwritten signature in black ink, appearing to be 'Paule Claassen', written over a horizontal line.

APPENDIX I:

Declaration of Language Editing
A RESEARCH THESIS SUBMITTED IN FULFILMENT
OF THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF ARTS IN SOCIAL WORK

By Barbara Van Rooyen

Student Number: 201090481

PERCEPTIONS OF PARENTS AND CAREGIVERS ON THE SPECIAL NEEDS OF
CHILDREN AT THE SUNSHINE DAY CARE CENTRE IN WALVISBAY

Has been edited by Dr Chamellé René de Silva

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