THE SUPPORT STRATEGIES OF FAMILIES LIVING WITH CHILDREN WITH INTELLECTUAL DISABILITY IN CAPRICORN DISTRICT, LIMPOPO PROVINCE, SOUTH AFRICA

by

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DECLARATION

I, **Mantji Juliah Modula (Student Number: 3062-854-7)** declare hereby that:

THE SUPPORT STRATEGIES OF FAMILIES LIVING WITH CHILDREN WITH INTELLECTUAL DISABILITY IN CAPRICORN DISTRICT, LIMPOPO PROVINCE, SOUTH AFRICA

is my own work, and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references, and that this work has not been submitted before for any other degree at any other institution.

Mantji Juliah Modula	Modula	15 February 2020
Student's name and surname	Student's signature	Date

DEDICATION

I dedicate this thesis to persons living with intellectual disabilities and their families who experience challenges and difficulties, striving for support services to enhance their wellbeing.

My heartfelt dedication also goes to my late grandparents, Modjadji Sophia and Pheagane William Modula for providing me with the foundation of education.

My children and my mother are not forgotten, for their unconditional love.

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ABSTRACT

Background: Deinstitutionalisation of people living with disabilities in communities encourage families to take caregiving responsibilities of raising children with intellectual disability (ID). This study explored and described the support needs provided to families of children living with ID at Capricorn District in Limpopo Province, South Africa, with the intention to develop support strategies that strengthen these families.

Method: A qualitative approach was employed, using both explorative and descriptive designs. Non-probability purposive and snowballing sampling methods were employed to recruit families who were directly affected and had the experience of caring and raising children with ID. Data saturation enhanced determination of the sample size. Twenty-six families participated in focus group discussions and one-on-one in-depth interviews to collect data at their homes. Inductive thematic analysis was used to categorise and organise the responses of the participants, which were then converted into intelligible statements with the assistance of Atlas.Ti version 8 computer programme.

Findings: The study findings were used to develop strategies to support families raising children with intellectual disability. In this regard, themes, categories and subcategories served as the evidence which primarily proved that families of children living with ID have limited support systems to enable their survival under challenging circumstances.

Recommendations: Policy makers should develop legislative frameworks and guidelines that ensure effective support to the families of children living with ID. Such frameworks will facilitate rules and regulations, curriculum and programmes that enhance and strengthen family support systems. Intersectoral collaboration of different departments should address the challenges faced by the families. Furthermore, establishment of effective monitoring and evaluation support systems should enhance further support to these families.

Conclusion: The study findings provide detailed understanding of challenges experienced of families of children living with ID. In addition, the findings illuminate on these families' support needs, notwithstanding the systems of support already available for them to cope with the challenges they experience. The researcher envisages that the proposed strategies will facilitate provision of effective family support by all stakeholders to strengthen coping mechanisms of the families.

Keywords: child; family; family strengthening; family support; intellectual disability; needs; strategy

LIST OF ABBREVIATIONS

ANAPEHMCO	National Association of Parents of Children with Intellectual Disability in the Democratic Republic of Congo
CBR	Community-based Rehabilitation
CHHs	Child Headed Households
CRPD	Convention on the Rights of Persons with Disabilities
CRC	Convention on the Rights of Children
CSOs	Civil Society Organisations
DBE	Department of Basic Education
DD	Developmental Delays
DoH	Department of Health
DoSD	Department of Social Development
EAP	Employee Assistant Programme
ECD	Early Childhood Development
ECDD	Early Childhood Development and Disability
ECI	Early Childhood Interventions
FCI	Family-Centred Intervention
FHH	Family Headed Households
FPSP	Family Parenting Support Policy
FQoL	Family Quality of Life
HHE	Head of Health Establishment
HiAP	Health in All Policies
HIV	Human Immunodeficiency Virus
HRC	Human Rights Commission
ID	Intellectual Disability
IDD	Intellectual Developmental Disorder
IFSP	Individualised Family Service Plan
IMCI	Integrated Management of Childhood Illnesses
INSSSC	Integrated National Support Strategy Services
IQ	Intelligence Quotient
LSEN	Learners with Special Educational Needs
MDT	Multi-Disciplinary Team
MEC	Member of the Executive Council
MHCA	Mental Health Care Act
MHRB	Mental Health Review Board
MR	Mental Retardation
NDP	National Development Plan
NGO	Non-Governmental Organisation
NPO	Non-Governmental Organisation
OAU	Organisation of African Unity
PHC	Primary Health Care
PID	Profound Intellectual Disability
PSI	Parenting Stress Index
PLWD	Persons Living with Disability

PWD	Persons with Disabilities
PWID	Persons with Intellectual Disabilities
RDP	Reconstruction and Development Programme
RSA	Republic of South Africa
RtHB	Road to Health Booklet
SAHRC	South African Human Rights Commission
SAPS	South African Police Service
SASSA	South African Social Security Agency
UN	United Nations
UNICEF	United Nations Children’s Fund
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organization
WPF	White Paper on Families
WPRPD	White Paper on Persons with Disabilities

STUDY ‘MIND MAP’

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1.1 INTRODUCTION

This chapter basically presents an outline of the entire study. In this regard, the primary units of analysis in the chapter include: background and context of the study; the problem statement; the study purpose, objectives and related questions; definition of key terms; the study's significance; ethical considerations; as well as the layout of the chapters. It is worth noting that the sequential arrangement and structure of this chapter also depicts the thematic logic of the study in its entirety, as well as the interstitiality of both the theoretical and empirical premises of intellectually disabled children (Polit & Beck, 2017).

In its quest to promote the wellbeing and the rights of persons with disability, the United Nations General Assembly proclaimed the 3rd of December as the International Day of Disabled Persons. Article 7 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) stipulates that countries should ensure equal human rights and fundamental freedom of children with disability (United Nations, 2006:7). The promotion of these children's rights confirms and underscores the obligation to protect them from unjust treatment; and further encourages access to health, rehabilitation, education and protection from exploitation and maltreatment (UNICEF, 2007:14).

In the South African context, various regulatory mechanisms and institutional or organisational involvement ensure the protection of both intellectually and physically disabled persons. The Constitution of the Republic of South Africa (Act No. 108 of 1996) made disability-based discrimination illegal. The Act further guarantees, protects and promotes equality and human dignity of disabled persons. South Africa has several non-governmental organisations (NGOs) and mental hospitals providing care, treatment and rehabilitation services to persons living with intellectual or physical disability. The collective regulatory and organisational impetus has ensured that disability constituted one of the country's priorities on the national agenda. For this reason, the national disability rights awareness is commemorated annually between 03 November and 03 December in South Africa. The purpose for this awareness is to inform the public about the disability, and to integrate persons with disability into society (Foskett, 2014:10). Meanwhile, the Department of Health (DoH) has the responsibility to provide developmentally appropriate health care services for those who suffer from severe and profound intellectual disability (ID), many of whom also present with physical disabilities.

1.2 BACKGROUND AND CONTEXT OF THE PROBLEM

Disability refers to moderate or severe incapacitation of an individual’s normal functioning induced by physical, sensory, communicative or intellectual impairment (DoSD, 2009:22). The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) defines persons with disability (PWD) as those with long-term physical, psychological, cognitive, neurological, or sensory challenges which affect an individual’s interaction and functioning in society (United Nations, 2006:28). Intellectual disability (ID), also known as intellectual development disorder (IDD) replaced the previous terms, ‘mental retardation’ (MR) and ‘mentally handicapped’. The American Psychiatric Association (APA, 2013:33) describes ID as dysfunctionality which starts during the intellectual and adaptive developmental stages of an individual.

ID deficit factors are classified as mild, moderate, severe or profound impairment, in accordance with adaptive functioning rather than intelligence quotient (IQ). The American Association of Intellectual and Developmental Disability (AAIDD) refers to ID as disability that is distinguished by significant intellectual and adaptive behavioural limitations that emerge before the age of 18 years (Sadock, Sadock & Ruiz, 2015:1118). However, persons with intellectual disability (PWID) appear more disadvantaged than those presenting with other disabilities, including physical and sensory difficulties (WHO, 2011:4). The table below indicates the global disability functional levels in multiple-domains according to low or high income countries.

Table 1.1: Disability prevalence rates for thresholds 40 and 50 derived from multi-domain functioning levels in 59 countries

Population Subgroup	Threshold of 40			Threshold of 50		
	Higher income countries (standard error)	Lower income countries (standard error)	All countries (standard error)	Higher income countries (standard error)	Lower income countries (standard error)	All countries (standard error)
Gender						
Male	9.1 (0.32)	13.8 (0.22)	12.0 (0.18)	1.0 (0.09)	1.7 (0.07)	1.4 (0.06)
Female	14.4 (0.32)	22.1 (0.24)	19.2 (0.19)	1.8 (0.10)	3.3 (0.10)	2.7 (0.07)
Age Group						
18–49	6.4 (0.27)	10.4 (0.20)	8.9 (0.16)	0.5 (0.06)	0.8 (0.04)	0.7 (0.03)
50–59	15.9 (0.63)	23.4 (0.48	20.6 (0.38)	1.7 (0.23)	2.7 (0.19)	2.4 (0.14)
60 and over	29.5 (0.66)	43.4 (0.47)	38.1 (0.38)	4.4 (0.25)	9.1 (0.27	7.4 (0.19)
Place of Residence						
Urban	11.3 (0.29)	16.5 (0.25)	14.6 (0.19)	1.2 (0.08)	2.2 (0.09)	2.0 (0.07)
Rural	12.3 (0.34)	18.6 (0.24)	16.4 (0.19)	1.7 (0.13)	2.6 (0.08)	2.3 (0.07)

Source: World Health Organisation report on disability (2011)

Table 1.1 shows that countries with lower income rates have more prevalence of disabilities than higher income countries. The table further indicates that more women in low income countries live with disability than those in higher income countries. Furthermore, the rate of people living with ID over the age of 60 was reported to be higher globally. In lower income countries, high PWID prevalence rates were found to be in rural areas across the globe (WHO, 2011:27). The latter state of affairs is corroborated by various reports on the promotion of the rights of children with disability, who are mostly found in poor and low income countries that also lack basic necessities (UNICEF, 2007:5).

Table 1.2: Disability prevalence by age in South Africa

People Living With Disability		
Age group	Number (N)	Percentage (%)
5–9	447 843	10,8
10–14	161 828	4,1
15–19	108 738	2,6
20–24	99 665	2,4
25–29	100 371	2,5
30–34	96 274	3,0
35–39	108 559	3,8
40–44	132 672	5,5
45–49	189 774	8,7
50–54	225 498	12,2
55–59	233 735	15,6
60–64	216 572	18,7
65–69	184 428	22,7
70–74	186 401	29,4
75–79	148 452	36,6
80–84	120 001	44,5
85+	109 319	53,2
Total	**2 870 130**	**7,5**

Source: Statistic South Africa census profile of persons with disabilities report (2011)

In South Africa, the middle age from 50 years and above shows a gradual increase (12.7% to 53.2%) in the number of persons with disability. In addition, the disability prevalence rate of children aged 5 to 9 years shows an increase of 6.7% compared to the 10 to 14 years age category. The higher rate of the 5 to 9 year old children indicates the period which mild and moderate physical or intellectual disability is identified. However, congruent with WHO reports on early childhood development and disability (ECDD), most children with mild and moderate disabilities are unidentified until at school-entry in most developing countries (WHO, 2012:22).

South Africa is experiencing lack of reliable statistical information of persons with disability, which impacts adversely on the ability of the government to make decisive interventions aimed at integrating disability into mainstream programmes and processes (Foskett, 2014:4). Deficient statistical information compounds the situation in the event that children continue to be hidden by their families and cannot access any services envisioned in the Integrated National Strategy on Support Services to Children with Disability (INSSSCD) (DoSD, 2009:7).

Table 1.3: Estimated global prevalence of moderate and severe disability

Gender/ Age group	**Percent**							
	World	High Income Countries	Low Income Countries					
			African	Americas	South-East Asia	European	Eastern Mediterranean	Western Pacific
Moderate and Severe Disability								
Males								
0–14 years	5.2	2.9	6.4	4.6	5.3	4.4	5.3	5.4
15–59 years	14.2	12.3	16.4	14.3	14.8	14.9	13.7	14.0
≥ 60 years	45.9	36.1	52.1	45.1	57.5	41.9	53.1	46.4
Females								
0–14 years	5.0	2.8	6.5	4.3	5.2	4.0	5.2	5.2
15–59 years	15.7	12.6	21.6	14.9	18.0	13.7	17.3	13.3
≥ 60 years	46.3	37.4	54.3	43.6	60.1	41.1	54.4	47.0
All people								
0–14 years	5.1	2.8	6.4	4.5	5.2	4.2	5.2	5.3
15–59 years	14.9	12.4	19.1	14.6	16.3	14.3	15.5	13.7
≥ 60 years	46.1	36.8	53.3	44.3	58.8	41.4	53.7	46.7
≥ 15 years	19.4	18.3	22.0	18.3	21.1	19.5	19.1	18.1
All ages	**15.3**	**15.4**	**15.3**	**14.1**	**16.0**	**16.4**	**14.0**	**15.0**

Source: World Health Organization disability report (2011:30)

Table 1.3 above indicates that more females suffer from moderate and severe ID compared to males from both high- and low-income countries worldwide. The table also shows increased occurrence rates for persons with disability over 60 years in low-income countries, especially in South-East Asia. The global rate of disability among children under the age of 14 years was low. Furthermore, lower-income countries encounter higher rates of mild to moderate ID, which is a manifestation of poverty and deprivation that undermine the development of vulnerable children (WHO, 2012:22).

Table 1.4: Distribution of persons from 5 years and older suffering from disability in South Africa

Gender and Level of Disability					
Type of disability	Gender	Mild difficulty		Severe difficulty	
		Number	%	number	%
Seeing	Male	1 604 318	7,6	279 553	1,3
	Female	2 481 581	10,9	458 526	2,0
	Total	4 085 898	9,3	738 079	1,7
Hearing	Male	545 433	2,6	127 271	0,6
	Female	706 475	3,1	161 098	0,7
	Total	1 251 907	2,9	288 369	0,7
Communication	Male	225 018	1,1	97 450	0,5
	Female	248 432	1,1	93 832	0,4
	Total	473 450	1,1	191 282	0,4
Walking Climbing stairs	Male	426 317	2,0	172 044	0,8
	Female	673 818	3,0	251 135	1,0
	Total	1 100 135	2,5	423 179	1,0
Cognitive (Remembering Concentrating)	Male	570 561	2,7	187 095	0,9
	Female	834 537	3,7	269 084	1,2
	Total	405 098	3,2	456 179	1,0
Self-care	Male	389 097	1,9	288 597	1,4
	Female	448 266	2,0	300 273	1,4
	Total	**837 363**	**2,0**	**588 869**	**1,4**

Source: Statistic South Africa Census Profile of Persons with Disabilities Report (2011)

According to Statistics South Africa (2011:12), persons with mild and moderate vision difficulties were high (11%), followed by those with cognitive, remembering and concentration problems at 4.2%. However, there is no indication of the number of children with specific type of disability.

Many young PWID manifest complex health problems that need clinical interventions to sustain life (Brown, Hoyle & Karatzias, 2016:535). The children often need assistance in a well-functioning family to meet their developmental and physical wellbeing. Consequently parents evolve to become distinguished caretakers of their children (Douglas, Redley & Ottmann, 2017:2739; Wilder & Granlund, 2015:133).

The Department of Social Development published the White Paper on the Rights of Persons with Disabilities (WPRPD) in 2016 for public information. The paper adopted the Disability rights Charter from the Freedom Charter. The South African government established the Office of the Status of Disabled Persons (OSDP) in the Presidency, which is charged with monitoring implementation of the Integrated National Policy Disability Strategy (INPDS) in all governmental departments.

The WPRPD asserts social rights of children with ID, including education, health care, housing, transport, sport activities, recreational facilities, culture, social development, nutrition and healthy family life. Furthermore, the paper posits that ID affects individuals and impacts on family members who live with the person with ID (DoSD, 2016:33). However, the INSSSCD have shown that children experiencing intellectual and forms of disability in Limpopo Province were particularly marginalised, with limited support coupled with in equitable availability of services (DoSD, 2009:11).

In the late 1990s, the global initiative to deinstitutionalise less disabled people amongst communities was undertaken. In South Africa such an initiative was introduced in 1997 (Foskett, 2014:25). The deinstitutionalisation encouraged PWID to stay with family members in a community setting where their lives can be appreciated (Anderson & Bigby, 2017:100). However, there are still PWID who still live with stigma and isolated from their communities (Capri, Abrahams, McKenzie, Mkabile, Saptouw, Hooper, Smith, Adnams & Swartz, 2018:12).

All children have the right to be part of the biological, adoptive or foster family, than be institutionalised, which would separate them from their families. Institutionalised children were mostly exposed to inconsistent caregiver input, poor nutrition, neglect, social isolation, abuse, poor stimulation, and lack of rehabilitation ECDD (WHO, 2012:15).

Article 23 of the UNCRPD posits that children suffering from disability have the right to family life and support from family members (United Nations 2006:16). However, most children live with their families who provide direct lifelong support (Beighton & Wills, 2017:326). The family is the most critical factor for the survival and wellbeing of children with ID. It is in this context that Article 23 of the UNCRPD stresses the rights of children with ID to special care subject to the availability of resources to the families providing care to such children (United Nations, 2006:15). The WPRPD identified the role of the family as provision of resources including, food, shelter, love, and support of the children with ID (DoSD, 2016:74).

The paradigmatic reorientation of PWID towards a model of community-based rehabilitation (CBR) through deinstitutionalisation has increased the burden of care for family members (Irazabal, Poster & Molina, 2016:10). As the primary caregiver in the life of the child with ID, the family faces their own difficulties in providing normal expected life functions in most cases (Adithyan, Sivakami, John, 2017:75; Pan & Ye, 2015:352). As the principal and most permanent support setting to children with ID, the family also deserves supportive services to strengthen normal family life of its members (Irazabal, et al., 2016:8).

Nurturing a physically or intellectually challenged child presents a range of considerable demands to families, leading to their feeling of guilty, depressed and ashamed (Mas et al., 2016:59). People with ID are incapacitated to optimally contribute to their livelihoods, and mostly depend on the financial assistance by family members (Pan & Ye, 2015:360). The study by Rajan, Romate and Srikrishna (2016:707) found that in some families, parents were sufficiently resilient to bear the hardships associated with the upbringing of a child with ID. In such situations, the supportive family members were the most likely to experience increased stress levels that threaten the integrity of the family structure (Ahmad & Khanam, 2016:58). Stress levels could also be exacerbated by the public and self-stigma associated with some perceptions of raising a child with ID (Werner & Shulman, 2015:272). As such, the stigma reported mediating effects which could lead to family members experiencing low self-esteem and depressive symptomology (Cantwell, Muldoon & Gallagher, 2015:948).

Families are diverse and complex. As such, it is very important for professionals to examine and improve each family’s ability to survive together with the intellectually challenged child in order to enhance the family’s quality of life (Vilaseca, Gràcia, Beltran, Dalmau, Alomar, Adam-Alcocer & Simò–Pinatella, 2015:33). In South Africa, Family and Parenting Support Policy indicates that some children are raised by a sequence of primary caregivers, including female relatives of their parents, grandparents or own generation (UNICEF, 2015:92).

The rearing of any child by the family requires support and availability of resources (McKenzie & McConkey, 2016:531). The Family and Parenting Support policy stresses that the family is a societal unit, which requires ecological balance planted within supportive networks. Hence, support is focused on stability and general functioning of the family (UNICEF, 2015:8). In South Africa, the White Paper on Families (WPF) was published to improve the caring capacity of family members to ensure healthy families through economic participation and social cohesion (DoSD, 2012:15). The Families and

Marriage of South Africa (FAMSA) highlights the importance of maintaining functional family structures in spite of internal challenges that may be experienced. FAMSA is a formal national NGO operating to support individual families, organisations and communities. The fundamental goals of family support intended to encourage positive feelings towards the family to commence and continue proactively in taking appropriate steps to raise fulfilled children (Fujioka et al., 2015:1738).

It is evident that families of children with ID deserve maximum support (Irazabal et al., 2016:15), to the extent that research further studies should be undertaken to identify culturally appropriate support services for families (McKenzie & McConkey, 2016:531). The need for such further explorative studies is necessitated by the limited support to carers or families of PWID in their quest to survive their challenges (James, 2012:7; Douglas et al., 2017:2739).

1.3 STATEMENT OF THE PROBLEM

The fundamental problem being investigate in this study is premised on the support-related factors that characterise the experiences of families with children living with ID, and services allocated to them. Numerous research studies have indicated that family, social, and community support improves the negative effects and challenges of caring for a child with ID (Cohen, 2013:71). Contrastingly, few studies have been conducted on support experiences of families of children with ID in South Africa. The researcher found it necessary to assess and explore the support needed by the families to provide care, support and raise their children with intellectual disability. Critically, the following question arose: *What are the support systems needed by families to cope with the challenges of raising children with intellectual disability?*

Studies globally have shown that the needs of children with ID could be burdensome for families, and result in emotional and psychological stress factors (Akturk & Aylaz, 2017:343). Through proxy responses, Statistics South Africa periodically provides prevalence measures of disability in the country. In 2016, the national disability prevalence rates showed an increase from 7.5% to 7.7% from the 2011 census, with (Statistics South Africa, 2016). In the same year (2016), Limpopo Province had 6.4% of disability prevalence. The province had 19.1% of persons with disabilities who had access to disability grants in 2015 (Statistics South Africa, 2016:33; DoSD, 2016:36).

The deinstitutionalisation of children suffering from ID to their families promotes emotional, physical and psychological development in a home environment. It is in this regard that the South African Human Rights Commission supports the channelling of community resources for the effective deinstitutionalisation of people with intellectual disability (SAHRC, 2017:7). In its effort to provide a supportive environment, the Department of Basic Education (DBE) in Limpopo Province provides free transport services to take learners with ID to special schools, which is consonant with the right of every child to receive education and a safe home environment supported by family members and the community.

The researcher observed that families living with children with ID were not comfortable during long school holidays and unplanned closure of special schools when children have to remain home. Furthermore, in cases where the children were institutionalised, parents and families were not willing to visit the children as expected. Some families were not even responding to telephone calls from the institutions regarding information about their children. Meanwhile, institutionalisation of children with ID was affordable to financially well-off families.

1.4 PURPOSE AND OBJECTIVES OF THE STUDY

The purpose of this study was to explore and describe the support needs provided to families living with intellectually disabled children in Capricorn District, Limpopo Province with the intention to develop support strategies to strengthen these families.

The research objectives are basically a reflection of the specific measures taken to give meaning to the research purpose (Maree, 2014:66). Accordingly, the research objectives were articulated thus:

- Describe the demographic profile of children living with intellectual disability in Capricorn District of Limpopo Province.
- Explore and describe the challenges experienced by families living with intellectually disabled children.
- Assess the existing support programmes and services provided to families living with intellectually disabled children.

- Develop support strategies to strengthen families living with intellectually disabled children.

1.5 RESEARCH QUESTIONS

The researcher used both the research objectives and research questions to guide the development of the following research questions, which were derived from the problem and the purpose of this study (Grove, Gray & Burns, 2015:147):

- What are the support needs of the families living with child with intellectual disability?
- What systems and services are available to support the families of children living with intellectual disability?
- What strategies can be used to improve the support provided to families living with intellectually challenged children?

1.6 SIGNIFICANCE OF THE STUDY

The significance of the study is underpinned by the extent of its contributions to the particular body or field of knowledge in which the investigated phenomenon (e.g. support of children with ID) is located (Moule & Goodman, 2014). Accordingly, the outcome of the study will contribute to knowledge in the realm of support strategies developed for families of children living with ID. For policy-making, the outcomes will further provide evidence-based strategies for government departments to address the support needed by families of children living with ID. Furthermore, the study will improve planning and implementation of support programmes and systems that significantly enhance the quality of life of the families living with children with ID.

1.7 DEFINITION OF KEY CONCEPTS

The key concepts in this section denotes the theoretical and operational contexts in which they apply in this study (Brink, Van der Walt & Van Rensburg, 2012:92). The definitions of these key concepts was intended to allocate specific/relevant meaning and significance regarding the extent of support provided to families of children with ID (Brink et al., 2012:92). Accordingly, the following alphabetically sequenced key concepts in this study have been linked to the support needs of families living with children with ID.

1.7.1 Child

The study has adopted the definition of the child as a person below 18 years of age, as stipulated in the Constitution (South Africa 1996:12). In that regard, a child means a person under the age of 18 years, suffering from intellectual disability, living with either a biological or adopted family, and is dependent on the care and resources of the particular family for survival.

1.7.2 Family

The White Paper on Families in South Africa defines a family as a group in society that is either bound by blood relations (kinship); foster care; civil, customary or religious marriage; adoption; civil union or cohabitation (DoSD, 2012:3). Such relations transcend any physical or geographical location and residence. Family also refers to two or more individuals depending on each other for their physical, emotional and economic sustenance (Townsend & Morgan (2018:200). Furthermore, Schlebusch, Samuels and Dada (2016:412) define family as an interactively connected and complex social system that integrates family members, as well as their environment.

In this study, family refers to any member living and directly experiencing or involved in the emotional, physical and social care and supporting of the well-being of the child with ID.

1.7.3 Family Member

The Children’s Act (No. 38 of 2005) defines family member as a parent, grandparent, brother, sister, aunt, uncle, cousin or guardian with whom the child has significantly developed a psychological or emotional relationship (South Africa, 2005:113-14). In this study, family member denotes any person living with a child in one household, and has a close or direct relationship or involvement in the wellbeing and development of the child with intellectual disability.

1.7.4 Family Strengthening

The intentional process by means of which families receive the necessary support, relationships, opportunities and networks to enable their functionality and self-reliance (DoSD, 2012:3). The strengthening of families is propelled by viable family support structures/systems, and economically successful, thriving and nurturing communities. As it applies in this study, family-strengthening means supporting the family in its care- giving functions throughout the continuous process of raising the child with ID.

1.7.5 Family Support

The UNICEF (2015:12) stipulates that family support relates to a system of processes and activities directed at improving the functioning of a family in respect of child-upbringing and other activities in an environment supported by conducive formal and informal human relationships and other material and non-material resources.

For the purpose of this study, family support means both formal (professionals), informal (friends, relatives and community) and material resources (finance) received by the family to survive the challenges of nurturing the child with ID.

1.7.6 Intellectual Disability (ID)

ID denotes limitations induced by impaired cognitive functioning and adaptive behaviour which emerged in an individual before the age of 18 years. The cognitive limitations or impairments include reasoning, problem-solving and learning capacity; while adaptive impairments/limitations include conceptual, practical and social skills (Sadock et al., 2015:1118). In this study, ID means slow cognitive development or mild, moderate, severe or profound behavioural adaptation that stifle a child's overall growth and development.

1.7.7 Need

According to Blackwell's Nursing Dictionary (2014:382) a need denotes a lack of something that is required for basic survival. In this study, a need refers to something that is an essential requirement to promote, improve or enhance and enable a person to sustain a healthy normal life.

1.7.8 Strategy

A plan intended to achieve a particular purpose in a skilful way (Oxford Advanced Learner Dictionary, 2010:1475). In this study, strategy refers to the process of implementing planned ways of enhancing and improving the support provided to the families raising children with ID.

1.7.9 Support

Non-material and material and help or assistance provided to a person who is in a difficult or unhappy situation (Oxford Advanced Learner's Dictionary, 2010:1500). For this study, support refers to resources and strategies to promote development and well- being of a person in need; in this case, the person would be the family or child with ID.

1.8 ETHICAL CONSIDERATIONS

Ethical considerations relate to the moral and professional (and legal) obligations to which both the researcher and participants have to adhere during the course of their formal information sharing engagements (Grove et al., 2015:101). It is in this regard that ethical considerations characteristically regulate even the researcher's adherence to the administrative processes of the institutions that are directly affected or involved in the study and its outcomes by means of permission granted to the researcher to proceed with the study (Silverman, 2017:57).

1.8.1 Permission to Conduct the Study

The Research Ethics Committee (REC) of UNISA's Department of Health Studies granted formal permission for the researcher to commence the study (see Annexure A for the Ethical Clearance Certificate). Subsequently, consent for permission to conduct the study was also requested through application letters to the Limpopo Department of Health and the Capricorn District Health Senior Manager (see Annexure B and Annexure C). Both the Limpopo Department of Health and the Capricorn District Senior Manager consequently granted written permission for the study to commence at those study sites under their control (see Annexure F and Annexure G). Among some of the critical information, the request letters detailed the research topic, purpose and expected nature of participation in the interviews.

1.8.2 Informed Consent of Participants

The informed consent of the participants is essentially an indication and recognition, protection and safeguarding of the human dignity of participants (Polit & Beck, 2012:162). Therefore, recognising the participants' right to make autonomous decisions, the researcher was obliged to make a full disclosure of all aspects of the study. This was a non-negotiable consideration for the researcher, also considering the sensitivity of the subject matter; that is, support provided to families and children living with ID.

The full disclosure entailed the possible benefits of the study, voluntary participation and the right to terminate participation at any time during the interviews and focus group discussions. Participants were also informed of their right to raise concerns or ask questions regarding the study before participating in the interview. They could also refuse to participate, with no threat of reprisals or intimidation (Saldana & Omasta, 2018:193). Additionally, no financial rewards or promises were made. A statement of full disclosure appeared on the first page of each interview guide. Based on their understanding of all of the study's aspects, the participants then signed the informed consent form as an indication of agreeing to participate in in-depth individual and FGD interviews (see Annexure A) voluntarily and uncoerced.

1.8.3 Participants' privacy, anonymity and confidentiality

In this study, confidentiality was ensured by prohibiting unauthorised persons from gaining access to any information of, and about the participants (Flick, 2014:21). The collected information (raw data) was kept private and used only for the purpose of this project to protect participants. The researcher ensured anonymity by removing any information that could link a participant's identity to any particular individual responses. Alpha-numeric codes were used for identification, instead of names (Grove et al., 2015:106). This was consistently applied, even during the research report writing process. In addition, participants' responses will be digitally stored such that only the researcher has password access, after which the information will be destroyed after five years.

1.8.4 Beneficence and recourse

In essence, beneficence entails the researcher's obligation to "doing good" by protecting participants (especially vulnerable populations such as children with ID) from any form of emotional, physical, spiritual or psychological discomfort, harm or exploitation for the entire duration of the study (Kendall & Halliday, 2014:303). The researcher provided transport for some of the participants to reach the venue at which the focus group discussions were held. Participants were afforded the opportunity to present any complaints and questions. The researcher observed and monitored participants for any sign of psychological distress owing to the vulnerability of the group (Grove et al., 2015:108).

In compliance with the principle of recourse, the researcher duly informed the participants of their right to report the researcher's perceived violation of any of their human rights. To that effect, email contact details of the researcher's academic supervisor were provided to the participants. However, they were reminded that such contact was only for study related matters, and would not apply beyond the study. Based on the vulnerable circumstances of the children living with ID, the researcher ensured that family members participating on their behalf in the study were truthfully informed about the general purpose of the study and the use of its findings (Grove et al., 2015:101). The researcher did not constrain participants from fully expressing their views and feelings regarding the interviews. Most importantly, the researcher formally sought permission from the participants for the use of an audio recorder (Du Plooy-Cilliers, Davies & Bezuidenhout, 2015:269).

1.9 ORGANISATION AND STRUCTURE OF THE STUDY

The chapters of the study are organised and structured as indicated below:

Chapter 1: Background of the Study

The chapter presents a broad overview of the entire study, with particular reference to critical units of analysis such as: introductory and background information of the study; the research problem; significance of the study; purpose, objectives and related questions of the study; definition of key terms; ethical issues; as well as a brief outline of all chapters. All the units of analysis mentioned in this chapter are discussed in further detail in the ensuing chapters.

Chapter 2: Review of Literature

The chapter presents literature sources related to intellectual disability and family support as key concepts to enhance further understanding of this phenomenon. Reviewing of the relevant books, articles, policies and other reports was done to support to identify the concepts forming the basis of the investigation.

Chapter 3: Theoretical Framework

Maslow’s theory of motivation and needs constitutes the most integral aspect of this chapter. Of particular essence in this chapter, are the main principles of this theory and their relevance or applicability to the study on children with ID and exploration of support provided to their families.

Chapter 4: Research Methodology

As indicated earlier, the chapter elaborates further on the specific data collection and analysis approaches and processes undertaken to render this qualitative study significant for its achievement of its objectives. Research setting, population and sampling methods and processes were explained.

Chapter 5: Presentation and Interpretation of the Research Findings

Narrative statements on the experiences of participants were analysed. Descriptive analysis of biographic information was presented as well. Seven main themes emerged with their categories and subcategories. The researcher has referred extensively on pertinent literature to either support or disprove the participants' narrative statements.

Chapter 6: Discussion of the Research Findings

This chapter forms the basis for development of strategies to support families of children with ID. The analysed participant responses and their attendant themes identified in the preceding chapter, served as the basis and framework in terms of which the findings informed the strategy development approach.

Chapter 7: Support Strategies of Families Living with children with ID

The chapter is fundamentally a systematic integration of Chapter 5 and Chapter 6, insofar as support strategies were developed from data analysis from both Chapters 5 and 6 on support of families living with children with intellectual disabilities.

Chapter 8: Main Conclusions, Key Findings and Recommendations

This final chapter of the study reflects an integration of the realisation of study objectives; main conclusions of the study findings; as well as limitation of the study and recommendations to improve support to families.

1.10 CONCLUSION

The foundational aspects of this study were outlined in this chapter, which commenced with a brief introductory phase and background information. The research problem, study purpose, objectives and related questions were presented. The study's significance was also highlighted, followed by a definition of the key terms to provide better understanding of the contexts in which these terms were used. The range of ethical issues presented in this chapter reflect a dual dimension of these ethical concerns; namely, their researcher- or participant-centredness. The following chapter reviews literature and previous ID studies and support for families of children with ID.

CHAPTER TWO: REVIEW OF LITERATURE

- CHAPTER ONE: BACKGROUND OF THE STUDY
- CHAPTER TWO: REVIEW OF LITERATURE
  - 2.1. INTRODUCTION
  - 2.2. THE CHILD WITH INTELLECTUAL DISABILITY
  - 2.3. THE FAMILY OF THE CHILD WITH INTELLECTUAL DISABILITY
  - 2.4. THE SUPPORT NEEDS OF THE FAMILY
  - 2.5. CONCLUSION
- CHAPTER THREE: THEORETICAL FRAMEWORK
- CHAPTER FOUR: RESEARCH METHODOLOGY
- CHAPTER FIVE: PRESENTATION AND DESCRIPTION OF THE RESEARCH FINDINGS
- CHAPTER SIX: DISCUSSION OF THE QUALITATIVE FINDINGS
- CHAPTER SEVEN: SUPPORT STRATEGIES OF FAMILIES LIVING WITH CHILDREN WITH INTELLECTUAL DISABILITY
- CHAPTER EIGHT: CONCLUSIONS AND RECOMMENDATIONS OF THE RESEARCH STUDY

2.1 INTRODUCTION

Literature review forms an essential part of the research process (Brink et al., 2018:71). The researcher reviewed written (secondary) sources relevant to the support of families living with the children with intellectual disability (ID), which included published articles in periodicals or journals, Internet publications, encyclopaedias, theses, conference papers, dissertations, textbooks, clinical journals; as well as organisational and government regulations, reports and websites (Grove et al., 2015:165). Literature review was helpful insofar as enabling the researcher to refine the research topic; its investigated problem; the stated aim, objectives questions; the theoretical and methodological orientations; as well as the applicable data collection and analysis processes (De Vos, Strydom, Fouché & Delport, 2014:134).

Furthermore, the literature review process served as a systematic and explicit approach to the search, retrieval and synthetic management of multiple perspectives and independent studies undertaken both globally and locally of children with ID and support to their families (Babbie & Mouton, 2012:566). Accordingly, the process facilitated a framework for systematic conclusions, recommendations and identification of areas for possible future studies to guide both theory and clinical practice (Brink et al., 2018:71). LoBiondo-Wood and Haber (2014:59) identified the following purposes of reviewing literature in research process:

- Determination of the unknown and known factors of the problem;
- Determination of literature gaps and inconsistencies;
- Discovering conceptual questions and hypotheses;
- Generating useful research questions;
- Determining appropriate methodological approaches and data analytical processes premised on assessed merits and demerits of previous research findings;
- Determination of the need for refinement and/or replication of the identified study problem;
- Uncovering new practice interventions or revising new policies and protocols;
- Promoting evidence-based review and development of policies related to nursing practice; and
- Generation of clinical guidance on development of evidence-based practice projects.

In the context of this study, the reviewed literature contributed to the researcher's clearer conceptualisation and nature of the investigated problem in its broader context; that is, in a larger knowledge pool (De Vos et al., 2014:134). In conjunction with the empirically generated (primary) information and data, the written (secondary) sources complemented the researcher's efforts to discover the support needs of families living with children with ID.

2.2 THE CHILD WITH INTELLECTUAL DISABILITY

This section focuses largely on the nature, levels and status of intellectual disability; its contributory factors, diagnosis, challenges; and rights of children living with intellectual disability.

2.2.1 The Nature of Intellectual Disability (ID)

The term, 'intellectual disability' has over the years replaced its 'mental retardation' (MR) variant. ID is characterised by an intelligent quotient (IQ) of 70 or less and significant limitations in at least two aspects of daily living activities (Kosslyn & Rosenberg, 2014:248). ID is also called intellectual developmental disorder (IDD). It is characterised by a deficit or decrease in overall mental functioning, including: judgement, reasoning, planning, problem solving, abstract thinking, as well as experiential and academic learning (Sadock et al., 2015:1118). Such disorder results in global developmental delays in which one fails to achieve the anticipated milestones in some areas of intellectual performance (APA, 2013:31).

Intellectual performance includes problem solving and reasoning acumen, while adaptive behaviour includes conceptual, practical and social skills (APA, 2013:31). Adaptive assessment focuses on social functioning competencies, understanding of societal norms, and performance of everyday tasks; while intellectual functions focus on cognitive abilities (Sadock et al., 2015:1118).

ID is a broadly classified developmental disorder, with a larger classification that more broadly addresses conditions in which there may be physical, language, learning and behavioural impairments. In this case, developmental competence is impaired in children with ID (Crnic, McIntyre, Baker, Neece & Blacher, 2017:436).

2.2.2 Degrees and Levels of Intellectual Disability

Children with ID differ widely in their degree of disability or impairment, which could be classified as mild, moderate, severe or profound. The Diagnostic and Statistical Manual of Mental Disorders (DSM-5™) indicates that levels of severity in ID are determined in terms of adaptive functioning, and not on IQ scores. The four-fold severity levels of intellectual disability are classified according to their social, conceptual and practical domains (APA, 2013:34-35; Sadock et al., 2015:1119).

2.2.2.1 Mild intellectual disability

The conceptual domain of mild intellectual disability levels manifest itself in mostly academic skills such as writing, reading, writing, numeracy, managing time, and financial literacy. Mild ID represents approximately 85% of people with ID (APA, 2013:34). The child needs support in this regard, in order to meet expectations in tandem with his/her developmental age. In the social domain, mild intellectual disability expresses itself through linguistic, communication and conversational difficulties. The impairment also results in difficulty to regulate emotions and behaviour. Moreover, there are limitations in understanding of risks in social environments and manipulation by others (gullibility) owing to immature social judgment. The practical domain premises on the child’s need for some support required for functioning appropriately within the age developmental expectations of personal care.

2.2.2.2. Moderate intellectual disability

The conceptual domain of children experiencing moderate ID shows slow development of language and pre-academic skills. Cognitive ability in reading, mathematical, writing and understanding of time and money occurs slowly and disproportionate to expected developmental age. The social domain shows slow developmental progress in social and communicative behaviour, in terms of which the child with ID only has relationships with family and friends. Although the child can perform self-care (e.g. eating, dressing, elimination, hygiene) as progressing to adulthood, the practical domain still shows maladaptive behaviour and social problems (APA, 2013:35).

Some parents of children with mild or moderate ID may mitigate the condition by frequently allocating greater responsibility to their children, offering them more choices and contact with other people to help these children understand their actions (Arellano & Peralta, 2013:179).

2.2.2.3 Severe intellectual disability

The conceptual domain of a child experiencing severe intellectual disability manifests with limited and poor linguistic, conceptual, quantitative, time, and financial understanding. Such limitations require provision of extensive support from the family. The social domain features of the child with ID display limited proficiency in language (vocabulary, grammar and speech) expressed in single words or phrases. Despite the child understanding simple speech and relationship with family members, the practical domain requires the family to assist and support the child with daily living activities; including eating, dressing and elimination. The child‘s maladaptive behaviour may expose them to self-inflicted injuries such as self-scratching, self-biting and hair pulling (APA, 2013:36).

2.2.2.4 Profound intellectual disability

Conceptual skills of the child with profound intellectual disability (PID) require physical development than typical ID procedures. In this regard, the presence of motor and sensory impairments limit use of objects in goal directed self-care skills. Social domains features of profound intellectual disability also limit understanding of both symbolic and gestural communication. Mostly, the child expresses own emotions and desires with nonverbal and non-symbolic means of communication, and further derives joy from relationships with familiar family members and caretakers or caregivers (APA, 2013:36).

Profound ID induces the practical domain of the child’s dependence on others with regard to basic living activities, including physical care, health and safety. The child enjoys basic recreational activities (e.g. listening to music) with the support of others. Therefore, the presence of physical and sensory impairments restricts the child’s capacity to participate in practical skills (APA, 2013:36).

2.2.3 The Status of Intellectual Disability in South Africa

The sparseness of reliable statistics in disability in South Africa has induced a state of uncertainty in PWID, rendering the government unable to develop coherent ID social policy (Foskett, 2014:4). Although foetal alcohol syndrome was found to be the most common ID cause in South Africa, other factors such as malnutrition, poor education and prenatal care also contributed to ID incidences (Foskett, 2014:4). As such, children with profound intellectual disability need lifelong care, supervision and assistance in specialised facilities to survive.

Nationally, the Mental Health Care Act (MHCA) (No. 17 of 2002) advocates that children with severe and profound ID should receive institutionalised health care, treatment and rehabilitation in authorised facilities. Most public mental health hospitals provide specialised care for PWID or special needs. The main purpose of institutionalising children with ID is to save life, protect them from harming themselves and others, and preventing possible damage to property.

In cases of public psychiatric hospitals' inability to accommodate intellectually challenged children, they are transferred to non-governmental institutions for State- subsidised care. In such instances, the State funds the NGOs for services provided. Some private institutions also provide PWID care funded by different sources rather than by government. However, the privately funded PWID institutions are still compelled to comply with stipulated MHCA admission procedures.

In keeping with the MCHA, the State provides PWID social grant to defray facility expenses incurred by the institutionalised person referred to a mental hospital or NGO by the State through the Mental Health Review Board (MHRB). The MHRB members are appointed by a Member of the Executive Council (MEC) for the Department of Health in each province as regulated by the MHCA (2002). The head of a health establishment offering services to PWID has the responsibility of reporting to the MHRB any admissions, progress and discharges in their institutions. Such reporting and its consequent communication between the head of the particular health establishment and the MHRB is documented procedurally as required by the MHCA.

Despite ongoing economic and educational difficulties, the State has introduced special schools for learners with special educational needs (LSEN) to cater for children with mild and moderate ID. Some of the schools provide boarding facilities for children who do not stay at home. Free daily transport service is provided to the special schools for the LSENs who are not in boarding. Additionally, the State-funded special schools provide health care services to the learners on a permanent basis through full time nurses and social workers. The nurses' services include medication and attending to minor injuries.

Nonetheless, there is still inadequate multidisciplinary health care services by other professionals and practitioners such as social workers, nutritionists, educational psychologists, as well as speech and hearing therapists (Adnams, 2010:439). The provision of such multidisciplinary health care services would enable proper identification and diagnosis of the intellectual disability challenges among children. These services would also reduce the overall material and non-material cost of managing the health of children living with intellectual disability.

2.2.4 Factors Contributing to Intellectual Disability

Intellectual disability results from the failure of the brain to develop properly from the foetal stage and during childhood. Researchers such as Kosslyn and Rosenberg (2014:250) and Sadock et al. (2015:1123) intimate that ID causes are basically genetic, developmental and environmental; all of which are discussed below.

2.2.4.1 Genetic factors

Intellectual disability could be transmitted in families genetically through conditions such as Down’s syndrome (caused by extra copy of entire chromosome 21); Fragile X syndrome; Prader-Willi syndrome (caused by small deletion of chromosome 15); Cat’s Cry (cri-du-chat caused by deletion in chromosome 5); and phenylketonuria (PKU, a metabolic defect in conversion of phenylalanine to paratyrosine). Other causes include Rett syndrome (diagnosed in the form of autism disorder caused by dominant X-linked disorder gene); neurofibromatosis (caused by a single gene); tuberous sclerosis (inherited by autosomal dominant transmission); and Lesch-nyhan syndrome resulting from a deficiency of enzyme involved in purine metabolism (Kosslyn & Rosenberg, 2014:250; Sadock et al., 2015:1123).

2.2.4.2 Developmental factors

The prenatal period is the most important period in the growth of the unborn baby, because maternal conditions and illness of a woman during pregnancy could affect the development of the foetus. Possible causes of ID that could aggravate the condition of a pregnant mother include: unmanageable diabetes, anaemia, hypertension, long-term use of alcohol, rubella, human immunodeficiency virus (HIV), cytomegalic inclusion disease and exposure to toxic drugs; including, heroin and cocaine (Kosslyn & Rosenberg, 2014:250; Sadock et al., 2015:1123). Pregnancy complications, including: vaginal haemorrhage, placenta praevia, premature separation of the placenta and cord prolapse, can cause damage to the foetal brain resulting in ID.

The perinatal period could have an impact on the development of the child, owing to problems at birth, including prematurity and low birth weight (Kosslyn & Rosenberg, 2014:250). Furthermore, childhood diseases and problems occurring after birth, including chicken pox and measles, could lead to meningitis and encephalitis and result in brain damage. Also, head accidents and injuries could cause asphyxia and damage the brain of the child, leading to intellectual disability (Kosslyn & Rosenberg, 2014:250; Sadock et al., 2015:1123).

2.2.4.3 Environmental factors

Environmental, poverty-related and cultural factors may have a detrimental influence on the developmental stages of the brain of the child. These factors include: environmental health hazards (e.g. X-ray exposure, lead or mercury poisoning); malnutrition; and inadequate medical care (Kosslyn & Rosenberg, 2014:250). These factors can also affect the development of the foetus, especially during the first trimester of the pregnancy. In addition, child neglect and inadequate care may lead to failure to address syndromes that affect brain development (Sadock et al., 2015:1123).

2.2.5 DSM-5™ Diagnostic Criteria for Intellectual Disability

According to Sadock et al. (2015:1120), the following DSM-5™ diagnostic criteria ought to be applied for intellectual disability in respect of its specifiers (i.e. mild, moderate, severe or profound):

- Limited intellectual performance (i.e. judgement, problem-solving, reasoning, abstract thinking, experiential and academic learning);
- Limited adaptive functioning, resulting in inadequate developmental and sociocultural responsibility and independence; and
- Emergence of adaptive and intellectual limitations during the developmental stages.

2.2.6 The Challenging Behaviour of Children with Intellectual Disability

Behavioural and psychological disorders are common in PWID. However, Medeiros et al. (2014:158) suggest that the behaviour displayed may be a sign for expressing attention, the need for stimulation, social escape, pain reduction, and tangible reinforcement (Medeiros, Rojahn, Moore & Ingen, 2014:158). Attention seeking and exceeding normal behavioural boundaries are typical in children with ID (Jacobs, Woolfson & Hunter, 2014:62).

2.2.6.1 Aggression

Aggression premises on deliberate offensive or attack actions towards other persons or objects (Medeiros et al., 2014:152). Such behavioural conduct among PWID is problematic, and reflects the degree of verbal, physical, or intellectual impairment. Mild and moderate ID usually present with verbal aggression, while severe and profound ID manifest in actions such as damage to property and self-harming behaviour (Medeiros, Rojahn, Moore & Ingen, 2014:15). Hence, some forms of strange aggression displayed during activities make it difficult to manage children with ID in classrooms (Crocker, Prokic´, Morin & Reyes, 2014:1033).

In most cases, the number of genetic syndromes contributing to ID show high levels of aggression. However, most reactive aggression displayed is part of a pattern of defensive behaviour among children with ID reacting angrily to a threatening or problematic situation (Willner, 2015:83). Swearing, pushing, grappling, pinching, spitting, throwing and breaking objects are some examples of aggressive behaviour that potentially jeopardise the public (Hewitt, Keeling & Pearce, 2015:162). Willner, (2015:83) has identified reactive and proactive aggression as the foremost types of aggression common to children with ID:

2.2.6.1.1 Reactive aggression

Reactive aggression refers to a behaviourally induced defence mechanism by which the individual tends to respond angrily to a problematic or threatening situation (Willner, 2015:83).

2.2.6.1.2 Proactive aggression

Proactive aggression is displayed with the intention to achieve a particular goal. It usually decreases with the severity of the ID (Willner, 2015:83).

2.2.6.2 Social withdrawal

Some children have difficulties forming relationships due to daily coping limitations associated with the ID impairment condition (Kumari, 2017:361). Such children were likely to develop regular social relationships, but could also experience comorbid attachment disorders when exposed to situations fraught with abuse, neglect and disruptions of attachment relationships (Giltaij, Sterkenburg & Schuengel, 2015:139).

2.2.6.3 Low self-esteem

Children with ID face mental and social problems, expressed as frustration, anger, sadness, and shame, which can lead to anxiety, depression and low self-esteem (Kumari, 2017:362). Some of the children may have difficulties in formation and maintenance of relationships with peers owing to the impairment limiting or restricting them from participating in everyday activities. Furthermore, low self-esteem/self-confidence in children with ID hinders development of their social clues, which would allow them to participate cooperatively with others and develop friendships (Kumari, 2017:362).

2.2.6.4 Stereotypical behaviour

Stereotypical behaviour or thoughts premise on subjectively assumed or perceived patterns of conduct, interests and activities associated with children living with intellectual disability (Medeiros et al., 2014:152). Such thoughts are not necessarily objective, but reflect an individual’s preconceived and prejudicial attitudes and worldview regarding a particular state of affairs or situation. For instance, the stereotypical view that children with ID cannot control their urinating and defecating functions, especially in public spaces, is problematic, inconveniencing, and embarrassing to most parents. Consequently, this makes it difficult for them to play with other children, who may themselves have been made to believe and adopt such views (Masulani-Mwale, Mathanga, Silungwe, Kauye & Gladstone, 2016:874).

2.2.6.5 Self-injurious behaviour

This type of behaviour has the potential to cause harm to the child with ID as a consequence of sensory and communication deficits resulting in the child’s inability to express himself/ herself. Common self-injurious behaviours in most PWID cases include head knocking, self-biting, self-scratching and hair pulling (Medeiros et al., 2014:151).

2.2.7 The Rights of Children with Intellectual Disability

The Constitution of South Africa (Act 108 of 1996) enjoins the State to respect, promote, protect and fulfil the individual and community rights enshrined in Chapter 2 of the Bill of Rights. Most importantly, the Constitution promotes the right to full equality, education and non-discrimination based on a person’s disability (South Africa 1996:5). Accordingly, all the human rights afforded other (intellectually able/unchallenged) citizens still accrue to children with ID. The following sub-sections detail the applicable rights to children with disabilities in the South African context.

2.2.7.1 The right to life

The right to life also entails every child’s natural entitlement to survival and to reach full potential, including protection against mortality rate owing to childhood illnesses (DOSD, 2009:23; South Africa, 1996:7). In South Africa, the Integrated Management of Childhood Illnesses (IMCI) programme was introduced into the health care services to identify illnesses and provide early treatment to reduce mortality rates, especially in children born from mothers with the human immunodeficiency virus. This programme is implemented at the primary health care (PHC) facilities.

2.2.7.2 Standard of living and to benefit from social living

Children with ID have the right to a safe and healthy environment that promotes their development. Therefore, these children require protection from neglect and malnutrition for them to survive. For this reason, the South African government provides care dependency and foster care grants for children with disabilities to assist their (DoSD, 2009:23).

2.2.7.3 Protection from abuse and the right to education

Children with mental disabilities are most vulnerable, and require protection from violence and sexual abuse from their families, institutions caring for them (including schools) and any member of society (DoSD, 2009:24). Education is a basic need and constitutionally guaranteed right in South Africa. As such, all children from the age of 7 (seven) are bound to attend school to access that right (DoSD, 2009:24).

2.2.7.4 The right to health care

Children with disabilities are vulnerable to comorbidity conditions, including epilepsy, autism and Down’s syndrome. In terms of the Constitution, these children are equally entitled to be provided with quality health care services, including sufficient food and water (South Africa, 1996:9). Children under the age of 6 (six) years are also entitled to receive free health care services (DoSD, 2009:24).

The White Paper on Persons with Disabilities attests to South Africa’s commitment to respect and implementation of the rights of persons with disability through the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and its optional protocols (DoSD, 2016:33). Commensurate with the UNCRPD recommendations, the following strategies should be adopted to promote and protect persons living with disability (PLWD) rights (DoSD, 2016:33):

- Strengthening the baseline of information relating to all UNCRPD articles;
- Strengthening implementation and mainstreaming of the UNCRPD legislative and policy structure;
- Coordinated targeting of interventions through integrated transversal policy and legislative monitoring mechanisms;
- Strengthening the UNCRPD’s national disability enablement framework and environments for disability organisations;
- Tightening accountability and monitoring by introducing rights-based disability indicators into governmental monitoring and evaluation systems; and
- Expediting disability-specific policy and programme implementation for equal access and participation by persons with disabilities.

In pursuance of the above-listed PLWD rights framework, the DBE produced Education White Paper 6 on Special Needs Education to meet the educational rights of children with disability. The paper outlines the need to transform the education and training system towards establishment of a caring and compassionate society to accommodate the learning needs of children with disability (DBE, 2001:11). In this regard, the paper uses terms such as “learners with special education needs” (LSEN) and “learners with mild to severe learning difficulties” as part of the approach to address the educational needs of children with disability (DBE, 2001:12). The Education White Paper 6 on Special Needs Education identified the following approaches of inclusive education and training to meet the rights of learners with special education needs (LSEN) (DBE, 2001:16):

- Accepting the learning and support needs of all children;
- Accepting and respecting the uniqueness and value of all learners with different learning problems;
- Implementing educational structures, systems, learning methodologies and teaching strategies for all learners;

- Acknowledging and respecting learner differences indiscriminate of age, class, ethnicity, gender, disability, language or HIV status;
- Acknowledging the learning occurring in the broader formal, informal and broader non-formal modes and structures within the home and community;
- Positive attitudes and behaviour in learning environments that are conducive to all learners' needs;
- Optimising learner active participation in the educational institutions' culture and curricula to minimize barriers of learning; and
- Empowering and involving learners as active participants in the process of learning.

2.3 THE FAMILY OF THE CHILD WITH INTELLECTUAL DISABILITY

A family includes parents, siblings, grandparents and other relatives and the child with intellectual disability (Vilaseca, Gràcia, Beltran et al 2015:41). Given the multi-factorial environment and diversity of individuals in the composition of a family, the following interrelated issues are presented in this section: the family as a system; types, structure, characteristics and functions of a family; including parenting and its impact in a family of an intellectually disabled child.

2.3.1 The Family as a System

Individuals in a family are closely engaged in the daily affairs of the household and are regularly supportive to one another irrespective of blood, personal or marriage relationships (Keltner & Steel, 2015:106). In most cases, changes affecting one family member causes a ripple effect change among other family members (Samuel, Rillotta & Brown, 2012:2). As such, the position an individual holds in a family influences the development of predictable characteristics of members (Townsend, 2015:2010).

The family represents a network of reciprocal relationship in which the experiences of each family member affect the entire family, and continue to change throughout the family's lifespan (Dalmau, Balcells-Balcells, Gine et al., 2017:642). Some families show different reactions to events like one member's diagnosis of a disease, birth, death, retrenchment and many more changes; especially in cases where support is needed. It is impossible to understand the care given to a disabled child without understanding the functions of the whole family (Turnbull & Turnbull, 1997 as cited in Cagran, Schmidt &

Brown, 2011:1166). Morse and Johnson (1991 cited in Morrison & Bennett, 2012:419) suggest the following stages for a family's adaptation continuum:

- Stage of resistance: denial or avoidance of the reality of disability by family members;
- Stage of restructuring: family members' reorganisation of their lives around changes in the family; and
- Stage of consolidation: new adopted roles remain unchanged, and new ways of thinking emerge.

2.3.2 Types of Families in the South African Context

Notwithstanding the multicultural nature of society in a country, the following types of families and households are known to be prevalent: nuclear; single-parent; extended; skip and three-generation household; polygamous; female- and child-headed; same-sex; cohabitation and migrant (DoSD, 2013:16):

2.3.2.1 Nuclear and single-parent family

The nuclear family only consists of parents and their biological or adopted children. It is the most known type of family in South Africa with the highest prevalence number (DoSD, 2013:16). On the other hand, a single-parent family is headed by one of the adults who is a parent and breadwinner of the children. In most cases, unemployment is the cause of the single-parenting (DoSD, 2013:18).

2.3.2.2 Extended and skip-generation family

The extended family is multi-generational family, and members may or may not share the same biological parents (Landers, Madigan, Leff, Rosati, McCann, Hornbake & Breese, 2016:263). In the South African context, extended families include uncles, aunts, grandparents, nieces, and cousins. Meanwhile, the skip-generation family refers to a situation in which grandparents participate in raising their grandchildren in the parents' absence. Such families are rendered fragile and vulnerable due to the grandparents' exposure to ill health and financial constraints. Hence, labour migration contributes to fragmentation of these families (DoSD, 2013:20).

2.3.2.3 Three-generation households and polygamous families

In a three-generation context, parents, their children and grandparents of their children, stay together as one household in the family. In other instances, the children's parents are taking care of the grandparents owing to their ill health (Landers et al., 2016:263). In a polygynous family, one man is married to more than one woman. Such families are mostly prevalent among rural African communities (DoSD, 2013:16).

2.3.2.4 Female-headed households (FHHs) and child- headed households (CHHs)

These are mostly headed by unmarried females who are also breadwinners alone by themselves (Velardo & Drummond, 2017:5). These families are at economic risk and poverty owing to inequalities and sexist societal attitudes that affect women. These families consist of a large number of children and are less likely to be economically active (DoSD, 2013:19). On the other hand, child-headed households (CHHs) are without adult family members, and children live in the absence of parents or prime-aged adults (Velardo & Drummond, 2017:6) In these families, the eldest child who heads the family has assumed parental responsibilities due to absence of the parents, owing to causes such as the migrant labour system. Mpumalanga and Eastern Cape provinces reported the highest prevalence of child-headed families at 0.8% (DoSD, 2013:20).

2.3.2.5 Same sex and cohabitating families

This type of marriage has been legalised since 2006 and registered under the Civil Union Act. Gauteng Province had the highest prevalence number at 391 in 2010 (DoSD, 2013 16:18). A cohabitating family, on the other hand, refers to a family in which partners or spouses stay together without legal recognition or protection in terms of property rights (DoSD, 2013:21). For these families to be legally recognised, they should enter into a cohabitation agreement (DoSD, 2013:21).

2.3.2.6 Migrant family

The migrant labour system is mainly responsible for the migrant family structure (Oliver & Barnes, 2012). In South Africa, migrant families come from rural areas to the urban centres for economic survival opportunities (DoSD, 2013:16). While the families are based in the urban areas, the have their permanent roots in the rural area from which they originated. A migrant family may come from another country to seek job opportunities in a host country, where they may face xenophobic violence from the public, discrimination and exploitation from prospective employers.

2.3.3 Characteristics of a Family

Ecological theory posits human development as consequential to the direct or indirect interaction of people in different life environments, including the home, neighbourhood or community (Dalmau et al., 2017:642). The ecological environment has induced changes in normal family characteristics due to the different types of family structures. Keltner and Steel (2015:108) have identified the following characteristics for normal functioning of the family:

- Caring and supporting their members, providing stability and unity to withstand external dynamics;
- Remaining together and providing predictability in unpredictable world;
- Protecting its members by caring for the vulnerable who are unable to care for themselves;
- Providing the platform of truth for children to learn communication, values and roles to enable them to function in the world; and
- Provides the basis to cope effectively with internal pressures.

2.3.4 The Functions of a Family

The WPF in South Africa identified the following functions and roles of families towards their members: membership and family formation; economic support; as well as nurturance and socialisation (DoSD, 2013:6).

2.3.4.1 Membership and family formation

The family has the responsibility of providing structure and sustainability within itself (Harrison, 2011:335). Each individual family member has to be supported and encouraged to develop their sense of personal and social belonging and identity, experience, and life purpose. With a strong leader within, the members of a family were more likely to function as a cohesive unit, which is a positive factor for the formation and future development of the family.

2.3.4.2 Nurturance, economic support and socialisation

The family should properly guide and provide the physical care, social values and norms, and mental and spiritual development of its members (Harrison, 2011:336). For its economic support, the family has the responsibility to provide sustainable processes and systems to alleviate poverty. In this regard, the family’s responsibility is most measurable by its capacity to meet the basic needs of its members, including food, shelter, clothing and security to its members. Family support also extends to the protection of its vulnerable members (Keltner & Steel, 2015:109). In this regard, the family is obliged to provide care and support to its young, sick and elderly members (DoSD, 2013:6).

2.3.5 Parents' Reactions to the Diagnosis of Intellectual Disability

Caring for an intellectually challenged child introduces a range of responses in different individuals and families (Douglas et al., 2015:2740). In most cases, trait-like personality characteristics of parents can influence how they will respond emotionally to their children with ID. However, their relationship with the child could also be influenced by children's behaviour problems (Griffith, Hastings, Petalas & Lloyd, 2015:584). Parents and caregivers of children with ID could also react with shock, denial and anger; guilt, self-blame and frustration; as well as pain, sadness and confusion (Uys & Middleton, 2014:546).

2.3.5.1 Shock, denial and anger

Shock is the first reaction towards the presence of the child with ID in the family, mostly because both the parents and siblings were not expecting such a condition of the child. The family assumed that they would give birth to a normal child who would be the same as others in the family (Douglas et al., 2017:2742). Shock generates denial based on parents not believing that the child belongs to the family. The denial and anger wear off as parents realise that the diagnosis of the ID condition was real and apparent. The victims of such anger are usually the midwives, doctors, partners, other children in the family, or perceived 'enemies' of the family.

2.3.5.2 Guilt, self-blame and frustration

Parents sometimes blame themselves and feel responsible for the condition of the child and what they could possibly have done to contribute to the birth of the child in that condition (Zechella & Raval, 2016:1296). Parents tend to think of the possible wrong things they might have done that contributed to the child's diagnosis, and inevitably become frustrated with the resultant care of the child. They have questions regarding the care demands of the child in the context of their limited access to resources. It is against such a background that they begin to consult different services expecting to receive assistance on the upkeep of the child. The family becomes frustrated when professional assistance fails to meet their needs.

2.3.5.3 Fear, despair and bargaining

The family develops fear of the unknown for the child and concerned with their ability to raise and take care of the needs of the child with ID, wondering whether the disability will ever improve (Douglas et al., 2017:2742). Parents even consult different services hoping for a different diagnosis of the child. Parents are imbued with a belief that the more they consult different institutions for help, the more possible it is to find remedies to the ID situation of the child (Zechella & Raval, 2016:1295). In such instances, parents seek for medical treatment beyond that provided a paediatrician or family doctor, but also the best and most renowned doctors (John, Bailey & Jones, 2017:675).

2.3.5.4 Sadness, pain and confusion

It is normal and necessary for the family to grieve for the ID diagnosis of a child which shatters the hopes of parents and dreams concerning the child’s future. The family becomes confused by the information provided by professionals regarding the diagnosis, care and support needed for the child. Consequently, their grief and loss represents their imagination, hopes and aspirations, leading to some of them becoming overprotective to the child (Zechella & Raval, 2016:1305).

2.3.5.5 Hopelessness, shame and feeling of inadequacy

Every family is hopeful of giving birth to a normal child. Hence, the birth of each child brings joy, relief and happiness to every family. It is for such reasons that the presence of the newly born child is viewed as life-changing (Zechella & Raval, 2016:1296). With the birth of a child with ID, the hope turns into an experience of shame and embarrassment that their child is not like other children. The condition of the child is viewed as defective, based on the child struggling to perform developmental milestones as expected. Thus, the parents may feel inadequate to meet all required needs of the child (Zechella & Raval, 2016:1296).

2.3.5.6 Envy, acceptance, disappointment and deprivation

Following the birth of a child with ID, the family may begin to envy those families of children without ID, and resentment at times (Zechella & Raval, 2016:1296). The panacea is for the parents to be content, accept and adjust to the diagnosis of the child; at which stage, they plan on how best they can help and care for the child.

Parents also experience disappointment about the plans made for the child and feel deprived of happiness and joy of witnessing the development and growth of their child. They feel robbed of the opportunity to contribute towards their child's betterment and preparation for a successful future.

2.3.6 Impact of a Child with Intellectual Disability on Parents

Parents as caregivers to children with ID are required to take necessary life-changing decisions in order to contribute to the child's best interests (Samuel, Hobden, LeRoy & Lacey, 2012:111). Consequently, taking care of the children with ID is both a positive and challenging experience for families (Nankervis, Rosewarne & Vassos, 2011:422). Parents of children with ID undergo a range of different emotions at different time of the child's upbringing, including (but not limited to) stress, anxiety, social isolation, psychological distress; depression, stigma and discrimination; as well as marital problems and their consequent divorce (Hooda & Gupta, 2017:1572; Wakimizu, Yamaguchi & Fujioka, 2017:38).

2.3.6.1 Stress

Disability is an unchangeable and continuous condition requiring unconstrained care for extended periods of time, which becomes difficult for some parents. The presence of the child with ID could be an emotionally burdensome and stressful experience that requires coping strategies for all family members (Akturk & Aylaz, 2017:243). Developmental problems of children with ID and excessive care are factors that mostly exacerbate the stress factors in families of the children with ID (Fujioka, Wakimizu, Tanaka et al., 2015:1726).Additional stress factors include financial strain, community isolation, lack of support, time spent in caring, and lack of leisure time (Crnic et al., 2017:438; Chouhan, Singh & Kumar, 2016:503).

The sense of lost felt by parents of the child with ID results in mental and physical problems which affect family quality of life (FQoL) (Gopalan & Sieng, 2015:1240). The parenting stress index (PSI) is a helpful tool for measuring the stress effects resulting from the unexpected birth of a child with ID. This tool consists of three main domains, namely: the child, parent and life stress domains (Abidin, 1995 as cited in Ahmad & Khanan, 2016:62). The parent domain consists of competence in caring; isolation; attachment; health; depression; and spousal support as stress causes (Abidin, 1995 as cited in Ahmad & Khanan, 2016:64). Baines and Hatton (2015:525) argue that, despite parents experiencing increased stress levels, they simultaneously feel they have become better persons through their parenting of the child with ID.

2.3.6.2 Anxiety, social isolation and psychological distress

The levels of anxiety depend on the severity and degree of ID of the child, whose care requires additional physical, emotional, social, financial resources and the child's multifaceted educational and developmental interventions (Chouhan et al., 2016:503). However, the level of parents' anxiety is usually determined by the level of stress experienced (Chouhan et al., 2016:503). Family members, especially parents, feel isolated from their communities, including from opportunities to make friends with new people (Wilson, McKenzie, Quale & Murray, 2012:8).

2.3.6.3 Depression, stigma and discrimination

Parents of children with ID, especially mothers, may experience targeted discrimination and stigmatisation or social isolation based on uninformed perceptions of giving birth to an 'abnormal' child (Kimura & Yamazaki, 2016:455). Stigma is reflective of prejudicial attitudes and discriminatory or stereotypical behaviours practised by individuals in particular social structures (Werner & Shulman, 2015:272). Perceived stigmatisation impedes access to support and identification of families who are susceptible to stigma (Cantwell et al., 2015:955).

Such gender-based discrimination could be compounded by the mother's unemployment, causing high stress levels and perennial stages of depression in the families of children with ID (Kimura & Yamazaki, 2016:455). However, the study by Hauser-Cram et al., (2001 as cited in Kono and Mearns, 2013:359) showed that both the mothers and fathers of children with ID experience high clinical levels of depression when their children reached the age of ten years and a proper school had to be found for the child.

2.3.6.4 Marital problems and consequent divorce

Marriage and long-term relationships are prone to disruptions by one partner who is always occupied with the care of the child with ID and the stress caused by the associated burdens (Duignan & Connell, 2015:204). While family relationships may be strengthened by the experience of providing care to an intellectually child, some families reported diminished intimacy and marital problem emanating from such experience (Duignan & Connell, 2015:204). The related strain of raising a child with special needs and behaviour problems could test both parents’ ability to cooperate and support each other and negatively impact on a marriage (Norlin & Broberg, 2013:562).

Tøssebro and Wendelborg (2015:128) report that a majority of studies experienced increased levels of stressful relationships among parents of children with ID. The failure parents’ emotional control and coping strategies could cause divorce problems and marital adjustment, including an unhappy sexual life (Kwok et al., 2014:1166).

2.3.6.5 Financial and employment burden

The unstable condition of the child with comorbid disorders, including genetic syndromes that need medical attention could result in high costs and financial burden for the affected parents (Zechella & Raval, 2016:1297). In this regard, the increasing medical costs and overall financial sustenance could exacerbate the financial difficulty for the family, especially in the event that one or both parents are unemployed (Saunders, Tilford & Fussell, 2015:42).

2.3.7 The Impact of the Child with Intellectual Disability on the Siblings

Owing to its complexity, multifaceted nature and variable impact on families, the challenges and experiences associated with ID can also impact on siblings either positively or negatively (Davys, Mitchell & Haigh, 2014:227). Furthermore, such impact on each individual sibling is different, and depends on a range of factors, including age, the degree of the child’s disability, family dynamics, understanding of the condition, availability of resources and planning for the future (Burke, Lee, Arnold & Owen, 2017:77). Other factors influencing other children’s adaptation to their sibling with ID include: behavioural challenges of the sibling with ID, household and caregiving tasks assigned to siblings, parental attention to favouritism among siblings, psychological state of parents, the extent of subsystem or network relationships in the family, as well as family financial resources (Choi & Van Riper, 2014:963).

2.3.8 The Reactions of the Sibling of the Child with Intellectual Disability

Since they all demand equal attention, the vital role of siblings contributes to the structure of the family and developmental growth of every child. Sibling relationships also develop and grow according to the nature of caregiving to the sibling with ID. The study by Rossetti and Hall (2015:127) identified that joy, guilt, frustration and stress constituted the salient forms of children’s emotional reaction to their sibling with ID.

In the above-cited study, the siblings expressed their happiness of being together with their sibling with ID. Such joy was viewed as a mitigation for the ongoing challenges of child care. The joy was also expressive of more effort to meet sibling care demands.

In the self-same study by Rossetti and Hall (2015:127) referred to earlier, the siblings showed feelings of guilt for failing to schedule time spent on care of the child as a recognised family member. Siblings further expressed their frustrations and sadness for not interacting sufficiently with the child because their sibling was mostly isolated with the mother. Consequently, the siblings developed stress resulting from concerns about the condition and pressure of helping to care for their sibling. The children’s stress is antithetical to their joy, and could further worsen the situation for those with comorbidity conditions, including epilepsy.

2.3.9 Parental Approaches to the Needs of Intellectually Disabled Children

The study by John et al. (2017:675) identified that the medical approach and family members’ agency were used by parents to approach and manage the daily and long-term care of their children with ID.

2.3.9.1 Medical approach and alternative treatment

Most parents invest in medical resources by searching for the best doctors and ID specialists for treatment of their children (John et al., 2017:676). Such medical investment is propelled by the parents’ unwavering belief that they will find answers from the doctors and ID experts concerning the condition of the child. Some parents also ensured that the schools complied fully with the special needs of their children, and provided support and empowerment to parents.

Alternative therapies were employed to, when parents’ interactions with doctors did not produce the desired outcome for improving their children’s condition. Many parents resorted to professionals such as physiotherapists to restore mind and body balance and to provide time for one-on-one interaction with their children. Some of the parents opted for approaches such as religious healing, meditation or electromagnetic therapy to remedy the child’s condition (Zechella & Raval, 2016:1298).

2.3.9.2 Personal agency and family members’ support

The families of children with ID are the main primary caregivers. The caregiving role played by family members is very crucial, especially the mother and siblings of the child with ID. Such a role is a demonstration of the indispensable socio-emotional and pragmatic support (UNICEF, 2015:8).

Personal agency focuses on the mother’s action-oriented approach to cope with the diagnosis of the child and her own ability to impact the development of the child. Mothers of children with ID channel most of their time and effort to activities that facilitate and stimulate their child’s development (Vilaseca, et al., 2015:37). More importantly, they research for knowledge on how to stimulate the speech, teaching numbers and letters, engaging them in leisure times to encourage them to be independent.

2.3.10 Caregiving Burden of the Child with Intellectual Disability

Caregiving burden refers to the demands, responsibilities and challenges that have negative consequences of caring for family member or relative with special needs (Kirby et al., 2015:32). Uys and Middleton (2014:89) corroborate that caregiving burden is the significant stress resulting from continuous, long-term caregiving of family member. The latter authors further identified symptom-specific, as well as emotional, social and financial burdens as forms of challenges of caregiving. Symptom-specific burdens manifest with the family taking the responsibility of ensuring supervision and assistance for the child, including the treatment of medical problems and behavioural challenges.

Caregiving of the child with ID impacts on the mental status and emotional wellbeing of families of children with ID, whose birth and presence in the family has many implications on the social relationships of the family and the community. Moreover, the family experiences financial strain related to the special needs of the child, including food, transport and medical services.

2.4 THE SUPPORT NEEDS OF THE FAMILY

Family support is defined as a family-centred and value-based approach directed by the needs of the family and the member with intellectual disability, focusing on the strengths, diversity and capacity of the particular family (Reynolds 2011 as cited in Samuel, et al., 2012:112). The family and parenting support policy indicates that family support considers the family as a social unit characterised by balanced ecological surroundings (UNICEF, 2015:8). The mutual goal of family support is to assist the families achieve contentment and self-efficacy in raising the child with ID by themselves (Fujioka, et al. (2015:1726).

Kleefman, et al. (2015:50) categorised family support into formal (organised or statutory sector), informal (family or friends) and semi-formal (community based or voluntary sector) variants. In addition, Aldersey, Turnbull and Turnbull (2016:24) indicate that family support responds to the family's physical, emotional, material or instrumental and informational needs. In addition, supporting parents with children with ID encourages them to perform satisfactory child caregiving duties and increased opportunities to be more involved in the activities of their children (Wade, Llewellyn & Matthew, 2015:35).

The support services offered to the families of children with ID should consider positive perceptions as a key factor wards the children's well-being and FQoL (Ferrer, Vilaseca & Bersabé, 2016:884). These support services include information centres, special schools, occupational therapy services, nursing homes and physiotherapies. The promotion of the wellbeing and enhancement of resilient families of children with ID can also inculcate a culture of positive perceptions (William & García, 2016). The following reasons are ascribed to the support allocated to the families raising children with ID Douglas, et al., (2017:2739):

- Parenting a child with ID can result in a stressful experience;
- Support enables the family to adjust and develop the necessary skills of care to their child with ID;
- It enhances professional support to help understand the crucial circumstances of the family of the child with ID;
- Families require holistic support to effectively take care of the child with ID;
- Provision of holistic support, which could have been limited erroneously by health professionals to the families of children with ID; and.
- Training and capacitation of professionals, including nurses and midwives will help recognition, understanding and addressing family support programmes.

The entire family unit needs family support services in the form of respite care and assistance; information and guidance; financial assistance; household support and adaptations to family transport (Vilaseca et al., 2015:37). Mostly, families who receive information support experience less anxiety, stress and depression, and have the confidence to manage their intellectually challenged children. It is for this reason that parent training or instruction interventions would be effective to support the family on how to take care of the child. The following sub-section outlines family support approaches emanating from the White Paper on Families in South Africa.

2.4.1 White Paper on Families in South Africa

The White Paper on Families is a policy document of the Department of Social Development aimed at mainstreaming family issues into government policymaking initiatives for the purpose of enhancing family well-being. The White Paper is concerned with protecting the human rights, ensuring family diversity, promoting family resilience and community participation, promoting and strengthening marriages and enhancing responsible parenting (DoSD, 2013:8). In this regard, the study has adopted the below-mentioned basic approaches to support families.

2.4.1.1 Rights-based approach

This approach is based mainly on promoting human rights, and is embedded in the constitution of the country. The approach is directed towards the protection of the human rights to social justice, minimum standards of living and equitable access to services to sustain the well-being of all individuals and families. Furthermore, the interaction with families should promote respect in their diversity and allow them to make informed decisions (South Africa, 1996).

2.4.1.2 The empowerment approach

This approach aims at strengthening the support, access and affordability of families to resources (DoSD, 2013:8). Empowerment is applicable through the process of assessment, intervention and evaluation to help strengthen the families who are in need by virtue of their support to children with ID. As such, empowerment strengthens these families by advancing the abilities, values, interests, resources, and accomplishments of the life cycle process for development of self-empowerment capacity of the affected families. To a large extent, this approach acknowledges the strengthening of marriages, parenting abilities and responsibilities to promote functional families.

2.4.1.3 Life cycle approach

This approach focuses on the concept of development, role and relationships in families. It stresses the dynamic nature of the family, and the role of each individual member in advancing the process of development (Fujioka et al., 2015:1726). The approach guides the provision of the support services to enhance family survival throughout the process of development including, parenting skills.

2.4.1.4 Systems approach

The systems approach views the family as a composite unit (Vilaseca et al., 2015:38). In this approach, the family is further viewed as a social system in which members are interdependent on each other’s behaviour. The approach is concerned with the stability of the family to maintain the general well-being of each member.

2.4.1.5 Social development approach

The approach emphasises the ontological nature of a family as the fundamental constituent part of society, which plays a vital role in the survival of families (DoSD, 2013:36). No family can live in isolation and develop without the support of the community. Figure 2.1 below indicates the key factors that promote the welfare of the child and the family, with the contextual domain as a leading factor in family and parenting support. In terms of this diagrammatic representation, the role of different stakeholders is emphasised, including NGOs, civil society and intergovernmental organisations and community, professional groups and other significant role players in accordance with UNICEF’s (2015:9) assertion. The architecture of family support and its dynamics varies from country to country according to social, care and psychological services and establishment of monetary support to the families (UNICEF, 2015:15).

The UNICEF’s (2015:10) family and parenting support policy (2015:10) embraces four levels of clusters or factors for any proposed framework for family and parenting support. These are: context, driving influences, modalities of policy and provision and outcomes. Figure 2.1 below is of particular relevance insofar as indicating the relationship between the State and different organisations and societies in the development of policies to support the families.

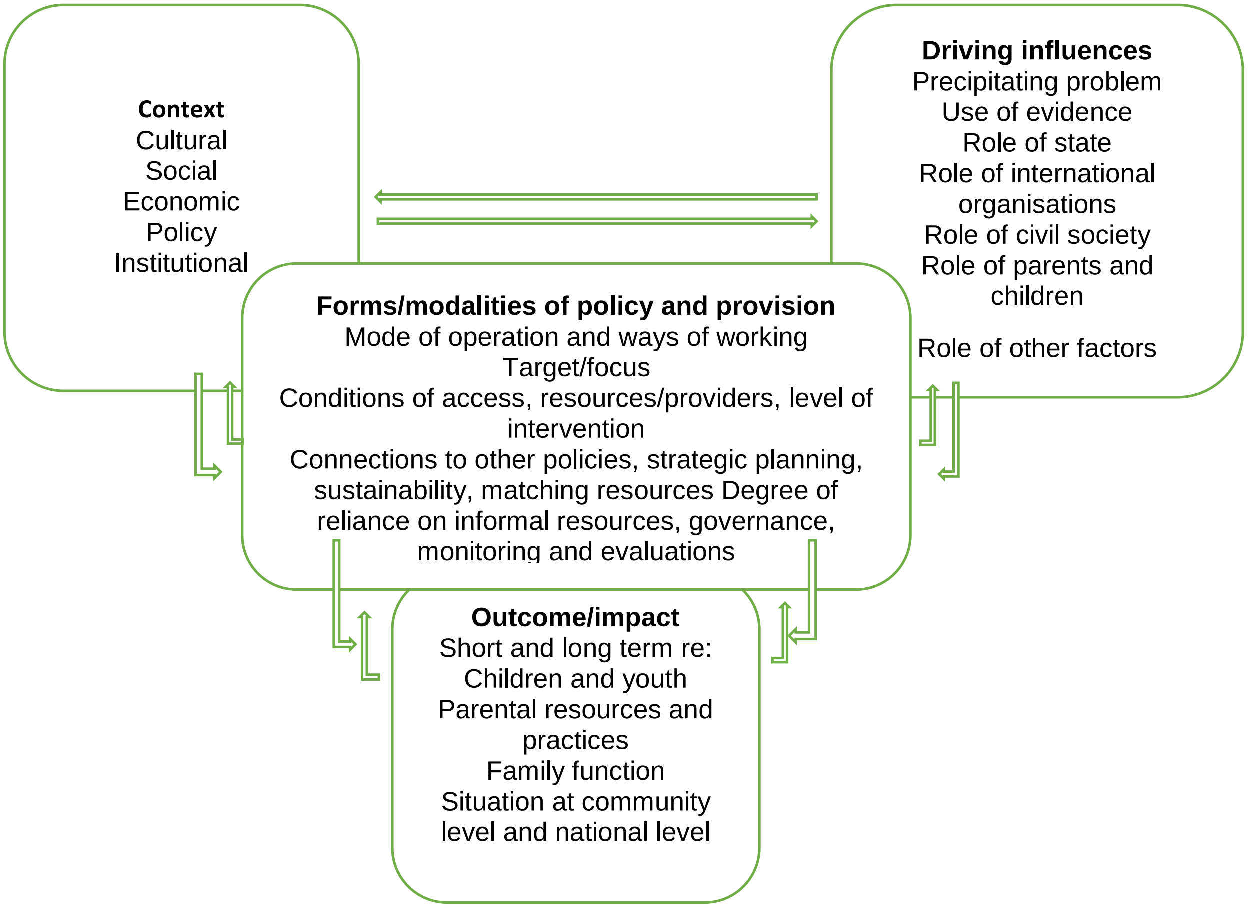

Figure 2.1: Comprehensive framework for the analysis of family and parenting support

Source: United Nations Children' Fund (UNICEF), 2015:10)

2.4.2 Formal Support

Parents of children with ID need frequent and early contact with support service providers owing to the complex needs of their children (Jansen, van der Putten & Vlaskamp, 2012:440). Partnership between professional service providers and families is essential to meet the children's needs. The partnership provides collaborated shared experiences, information and decision-making on the care of the child (Jansen et al., 2012:440).

Globally, the provision of support services is changing from the professionals as superior, to the family-oriented model according to which parents' wishes are prioritised in collaboration with professionals (Fujioka, et al., 2015:1726). According to James (2012:21), the below-cited roles are recommended for professionals to support the families of intellectually disabled children:

- Professionals should provide clear, understandable information related to their child's condition and treatment;
- Professionals should provide psychological support and equip the family with skills to enable them to manage in difficult times;
- Professionals should, on account of their skills and knowledge, coordinate effective family services;
- Professionals should give advice and required support to enable them to be in control of their situation; and
- The formation of partnerships with the family should advance the identification of the various support related problems, planning and decision-making about the type of support necessary for maintaining effective communication.

It is noteworthy that the provision of family support services by professionals should aim to develop individualised family service plan (IFSP). In addition, IFSP plays an important role in supporting families and promoting their wellbeing, irrespective of their demographic characteristics or socio-economic circumstances (Ferrer et al., 2016:884). Following below are various roles and therapies to support the families as articulated by Townsend and Morgan (2018:212).

2.4.2.1 Joining, evaluating and restructuring the family

The therapist becomes part of the family, but takes the lead in restructuring of the family and including family members as the target of the restructuring intervention. The behaviour of one member affects the entire family. The therapist must evaluate and assess the family for transactional patterns, role of members, developmental stage, flexibility and potential for change. The therapist further establishes a therapy contract with the family by being part of them, which enables manipulation of the system according to the circumstances and experiences of family members who can contribute to structural change.

The family's competence to manage the challenging behaviours of children has the potential to lower family stress (Mulligan, John, Coombes & Sigh, 2014:165). Professionals ought to be competent in identifying the challenges of families. It is on the basis of such competence that professionals may provide the required flexibility for parents to contribute to the social and educational programmes of their children. Building communication and collaboration between professionals and parents enhances satisfaction and improves learning outcomes for children with ID (Al-Kandari, 2014:122).

2.4.3 Informal Social Support

In South Africa, informal support from friends, relatives and neighbours plays a larger role to support the families. According to the UNICEF's family and parenting support policy, the support includes food, shelter and care of the child (UNICEF, 2015:93). Guzowski (2017:27) emphasises that social support offers aid and coping strategies relevant to the context of the problematic, critical, difficult and stressful situations. The latter author further identified the following types of social support discussed below:

2.4.3.1 Structural and functional support

Structural support refers to social networking available in the individual's environment (Boehm & Carter, 2016:73). It is a foundational form of support, which consists of both informal and formal help. Functional support refers to roles and quality of social interaction supporting one another by passing or exchanging different kinds of resources.

2.4.3.2 Noticed and actual support

Noticed support refers to the acknowledgement by the family on available support system and subjective assessment of the support received (Park et al., 2003 as cited in Schlebusch, Samuel & Dada, 2016:413). Actual support received can be measured objectively and assessed by the family. Boehm and Carter (2016:74) also suggest that social relationships can shape the well-being of families living with children with ID.

2.4.4 Family Quality of Life (FQoL) Support

Zuna, Summers, Turnbull, Hu and Xu (2010) refer to FQoL as a dynamic sense of wellbeing of the family, collectively and subjectively defined and informed by its members to their needs and interaction. Meanwhile, Park et al. (2003 as cited in Schlebusch et al., 2016:413) refer to FQoL as the goodness of family life or the conditions in which family needs are fulfilled and family members enjoy life together, while they also have the chance to do other important things. From the point of view of Moyson and Roeyers (2012:87), FQoL is viewed as an important element in family support programmes. Such a perspective describes the family as a system focusing on their members' quality of life and their influence on each other. FQoL plays a significant role in studying, working, identifying and assessing any impact of the support services provided to the families for the enhancement of interactions with the intellectually challenged children (Ferrer, et al., 2016:872).

FQoL can be assessed by using FQoL-2006 and Beach Centre FQOL scale domain instruments focusing on variables such as health of the family; financial well-being; family relationships; support from others and disability-related services; influence of values; careers and their preparation; leisure and recreation; and community interaction (Samuel et al., 2012:5).

2.4.5 Peer or Support Groups

It is crucial for parents of intellectually challenged children to connect and advice each other. Such rapport provides them with the opportunity to share their experiences with people who faced similar challenges (Meral, Cavkaytar, Turnbull & Wang, 2013:234). Most parents linked to peer support groups benefited from psychosocial support and gained experiential knowledge regarding support services available within their communities (Douglas et al., 2017:2744). Friends, neighbours and retired parents are often preferred as strong support for the families of children with ID (King, Williams & Goldberg, 2016:336). The following roles of support groups to families and caregivers involved with ID, were found to be advantageous (Wei et al., 2011:1673):

- Support groups are an opportunity to share with members about caregiving experiences and understanding the impact of stress on their health;
- The group shares valuable information on issues such as physical and psychosocial health, including diet and nutrition, medical news, recreational sports and exercises, travel trips, charity events, and meditation;
- The provision of health education and counselling opportunities on stress and psychosomatic illness management to assist members to maintain good health;
- The provision on information on medical resources available to its members and their child with ID;
- The group atmosphere encourages and engenders closeness and trustworthiness among its members;
- Group interventions provide many opportunities for promoting interaction and transmission of information, which allows and encourages members’ multi-dimensional perspectives of situations;

- Practical suggestions and listening in group sessions improves members' mutual respect, which reduces their self- isolation and capacity for communal care;
- Group members are assisted with adaptive skills to train their children with ID on skills including, toilet training; and
- Groups enhance sharing of strategies relevant to securing assistance of various support structures, including NGOs and schools.

2.4.6 Material/Instrumental Support

Material support focuses on provision of direct physical actions of value, while instrumental support provides information or instructions to enable the family to respond to particular situations (Guzowski, 2017:27). Families receive support with payment for medications, healthcare or funeral costs related to children with ID. Some NGOs also contribute to provide families with equipment needed for improving daily living and health-related activities, including wheelchairs for the children (Aldersey et al., 2016:28). Families exposed to poverty and hardships need further material support to counter child neglect and abuse, living in poor neighbourhoods lacking shelter, violence, inadequate social services and education, unhealthy surroundings and conditions with long-term health consequences (Meral et al., 2013:242).

2.4.7 Spiritual and Religious Support

Spirituality refers to the human quality that allocates sense and meaningful purpose of an individual's existence (Townsend, 2015:109). Spirituality provides vital support when facing a crisis or the prospects of having an intellectually disabled child (Guzowski, 2017:27). It is further argued that most families view their religious faith as the greatest support and source of sustenance amidst the many burdens of caring for their children with ID (McKenzie & McConkey, 2015 :538).

There is a strong belief that a firm spiritual grounding could assist individuals to confront their daily life challenges and experiences (Townsend, 2015:110). Some previous studies have shown that Pakistani parents attributed their children's disability to either personal failure or God's will; whereas some Indian parents viewed such disability as either a curse from God or punishment for their past misdemeanours or sins (John, et al., 2017:670). As such, they left the future of their children in the hands of God. However, parents still feel that their caregiving effort is not in vain and continue to hope that God will reward them (Gallagher, Lee, Phillips & Carroll, 2015:364). Accordingly, such beliefs assist them to garner more strength to continue providing care to their children with ID and coping with the attendant challenges.

Spirituality assists parents to develop a defence mechanism to deal with the perceived guilt and shame of their child's diagnosis (Rathore & Mathur, 2015:343). However, religion was found to be a resourceful coping mechanism for parents to address the stress associated with the needed care for the children with ID (Baines & Hatton 2015:525). In addition, spirituality helps the families to cope with their children and accept them as God's plan or will (Gilson, Bethune, Carter & McMillan, 2017:348; Richie, 2015:75; Masulani-Mwale et al., 2016:876).

2.4.8 Community Support

In South Africa, community-based organisations (including non-governmental and non-profit organisations) are vital in providing support to families of children with ID. The development of community-based, training and leisure options assist to develop children with ID and support to families for coping with caring burdens (McKenzie & McConkey, 2015:540).

Disability services and parents' organisations in South Africa carry the responsibility of providing family support and empowerment programmes without any State support (DoSD, 2016:74). Insufficient community and family support and care services for their children with ID creates a high exploitation and abuse risk to children leading, to violation of their rights as human beings (Cohen, 2013:72).

2.5 CONCLUSION

The chapter provided information on the degrees and causes of intellectually disability, the behaviour of children with ID and the rights of people with ID. The literature also provided insights on the family as a support system with individual needs. The chapter further explored the impact of raising the child with ID on the family, including the reaction of family members, the needs of the family, support structures and legislation related to the rights of the family as caregivers to guide the study. Chapter 3 discusses the theoretical framework of the study.

CHAPTER THREE: THEORETICAL FRAMEWORK

CHAPTER ONE: BACKGROUND OF THE STUDY

CHAPTER TWO: REVIEW OF LITERATURE

CHAPTER THREE: THEORETICAL FRAMEWORK

- 3.1 INTRODUCTION
- 3.2 MASLOW'S THEORY OF NEEDS
- 3.3 CONCLUSION

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CHAPTER SEVEN: SUPPORT STRAGTEGIES OF FAMILIES LIVING WITH CHILDREN WITH INTELLECTUAL DISABILITY

CHAPTER EIGHT: CONCLUSIONS AND RECOMMENDATIONS OF THE RESEARCH STUDY

3.1 INTRODUCTION

The preceding chapter focused on the reviewed literature relating to intellectual disability (ID) and the family support. The current chapter discusses the theoretical framework that guided the study in its exploration and description of the support needed by families of intellectually challenged children in Capricorn District, Limpopo Province. A theoretical framework provides a narrative version of selected key factors, concepts, or variables as well as the assumed relationships that exist between such variables, concepts or factors (Polit & Beck, 2017:119).

The study's intention was to develop strategies to support and strengthen the families to cope with the demands of raising the children with ID. In this regard, the critical variable relates to the support needs of the families living with, and caring for the intellectually challenged children. Achieving family support for these children is multifaceted, and all efforts carried out to achieve a better quality of life are interrelated, and serve as the building blocks of association with Maslow's theory of the hierarchy of human needs and motivation. Therefore, the theory was relevant for the study's foundational tenet and focus on the children with intellectual disability's range of needs (LoBiondo-Wood & Haber, 2010:118; Uysal, Aydemir & Genc, 2017:211). Motivation involves desires, needs, drives, wishes, and interests that play a major role in encouragement to get into action (Uysal, et al., 2017:211).

3.2 MASLOW'S THEORY OF NEEDS

Abram Maslow was the first to develop the motivation theory in 1943, with the hierarchy of human needs playing the pivotal role to influence such motivation (Uysal et al., 2017:211). The motivation of needs entailed in this theory was used to develop a model describing a hierarchical (pyramid-like) organisation of needs present in every human being (Sadock et al., 2015:181). The pyramid-like organisation of needs were categorised into basic, psychological and self-fulfilment needs on different levels (Rahman, 2017:1736). In terms of the hierarchy, it is very crucial to deal with the needs closer to the base of the pyramid prior to those at the apex.

The five-tier model of human needs, commonly known as hierarchy of needs, is composed of the physiological, safety and security, love and belonging, self-esteem and self-actualisation needs crucial for human survival (Townsend, 2015:14). According to this theory, human needs are unlimited, continuous and considered dependent on one another (Uysal, et al., 2017:211). The ability to meet one level of needs motivates and enables the person to improve performance to satisfy more needs on the higher level (Townsend, 2015:14). Figure 3.2 below represents Maslow's theory of hierarchical needs, whose relevance to the study premises on its relational link to the seven thematically categorised needs of children with ID presented in Chapter 5 of this study.

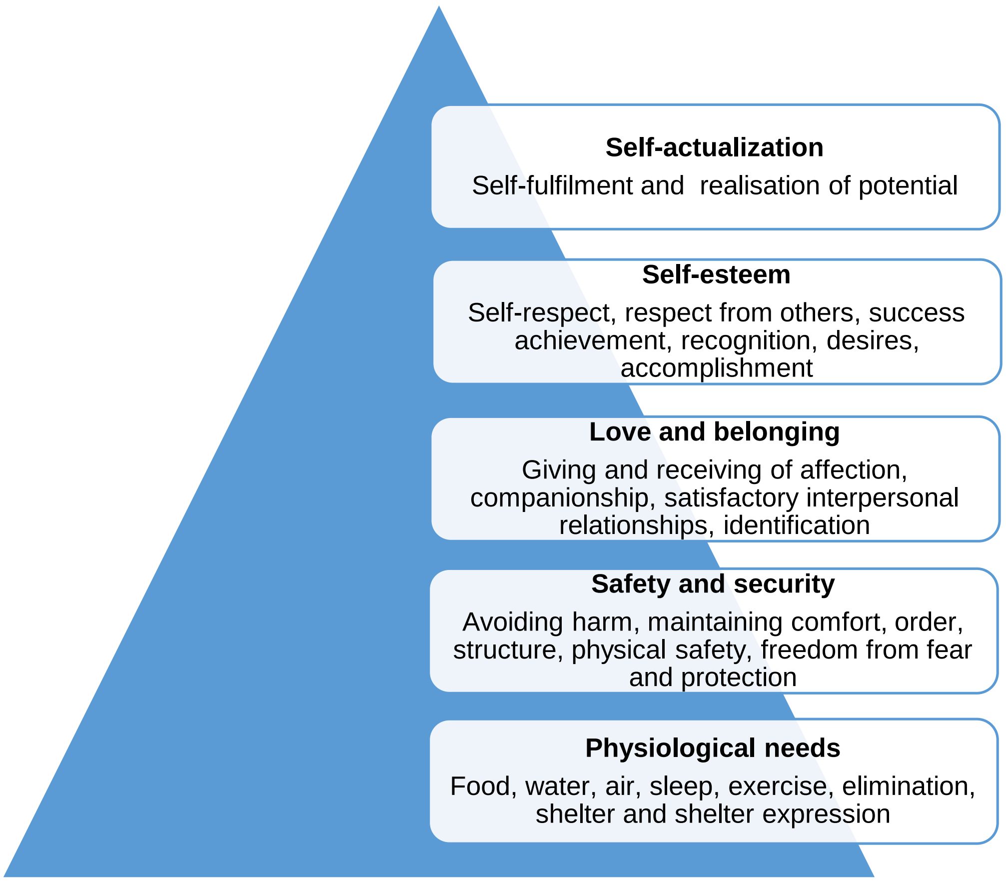

Figure 3.1: Maslow's hierarchy of needs
Source: Townsend and Morgan (2018:15)

The theory posits that human beings who grew up in an environment that disables them to meet their needs are unlikely to function well on daily living demands (Kaur, 2013:1061). The World Health Organisation's disability report indicates that, as a human function, disability can cause temporary or permanent difficulty in meeting human needs (WHO, 2011:3). Disability limits the person's opportunities to meet the needs of essential basic daily living, leading to dependence on family members (Omolayo, 2009:449). The persons with disabilities may be disadvantaged to perform optimally and meet their basic human needs resulting from lack of physical mobility or mental development (Townsend, 2015:734).

The American Psychiatric Association asserts that ID is characterised by deficits in mental capacity and social adaptive functioning (APA, 2013:33). However, ID results in a persons' inability to develop personal independence and social responsibility to meet their own needs (APA, 2013:33). The onset of the disorder occurs during the developmental stages of the person, causing deficits in the conceptual, social and practical domains (Townsend, 2015:734). Deficit in intellectual functioning leads to the inability of the person in problem solving, planning, judgement, learning, and abstract thinking (APA, 2013:33). Poor judgement and abstract thinking result in poor interpretation of the environment and inability of the person to protect himself or herself (Townsend, 2015:470). Consequently, poor problem solving, learning and planning are a demonstration of poor adaptive coping skills and response to stressful situations (Townsend, 2015:734).

Deficit in social adaptive functioning limits the ability to meet personal independent living and leads to poor social responsibility. In addition, the deficit leads to an individual's inability to adapt to social participation, independent daily living and communication required for continuous support and survival (APA, 2013:33). Lack of social participation results in isolation from others leading to poor environmental stimulation and communication skills to interact with others (Townsend, 2015:734). Furthermore, lack of social judgement in persons with ID may predispose them to exploitation and victimisation (APA, 2013:38).

No human being lives in isolation, and every individual belongs to a family environment. Children with ID become fully dependant on their family members; therefore, the diagnosis of ID extends the caregiving role of family members to the child (Rahman, 2017:1735). 'Family' refers to a unit and every individual linked to it. As such, impact on one member affects the entire family. The deficit in the level of self-care of the child with ID impacts on the functioning of the family (Samuel et al., 2012:2). However, promotion of the rights of children with disabilities posits that the stigma associated with disability of the child may cause the family not to report the condition of the child and lead to lack or denial of support (UNICEF, 2007:4).

The families as caregivers of the children with ID have important role of ensuring provision of their human needs. South Africa's White Paper on Families indicates the roles of families as nurturance, support, protection and socialisation in ensuring the wellbeing of the children with ID (DoSD, 2013:6). However, the families as the child's primary caregivers have responsibility to care and support children with ID, which ensures the fulfilment of their special needs (Rahman, 2017:1736).

The UNCRPD defines the family as the natural core unit within the society in which children with ID's needs require attention. Furthermore, the family deserves protection from society and the State in order to fulfil the needs of the individual member and dignity of the children with ID (United Nations, 2006:3). In 2007, South African government ratified the UNCRPD to implement the rights of persons with intellectual disability (PWID). The Constitution on the Bill of Rights chapter 2 protects the human rights to ensure dignity of PWID (South Africa, 1996:11).

In South Africa, children with ID in rural areas are most vulnerable as they live in extreme poverty (DoSD, 2009:7). Poverty limits the opportunities of the families to meet the basic human needs for the survival of the children. The DoSD provides care independency grant to children with ID to assist the families with financial relief. The White Paper on the Rights Persons with Disabilities stresses the importance of strengthening families to access the necessary opportunities, relationships and support to raise their children with ID (DoSD, 2016:7). The ensuing sub-sections (3.2.1-3.2.5) focus on the direct applicability of Maslow's theory to the current study.

3.2.1 Physiological Needs

Basic physiological needs are crucial for every human being to survive. This form of survival derives from food and water, sleep, exercise, elimination, warmth, shelter and sexual expression (Kneisl & Trigoboff, 2013: 82). These needs refer to those that are obligatory and determine the attainability of other needs (Uysal, et al., 2017:215).

The UNICEF (2007:6) acknowledges the importance of physiological needs, stating for instance, that iodine deficiency in food and poor access to water is a major cause of disability. The UNCRPD further posits that children and their families have the right to a healthy standard of living, which is achievable through adequate housing and clothing, which are basic physiological needs (United Nations, 2006:20).

Chapter 2 (Bill of Rights) of the Constitution of the Republic of South Africa stipulates that citizens have rights to health care, housing, sufficient food and water, including emergency medical treatment. In addition, the Constitution stresses the right of every child to basic nutrition, shelter and health care services, irrespective of disability (South Africa, 1996:11). This attests to the salience of care and support as an enabling factor for primary caregivers to meet the needs of children with ID (Rahman, 2017:1736).

3.2.2 Safety and Security Needs

Once the human being's physiological needs are fulfilled, the person will move towards safety and security needs. The concept of safety includes preventing harm, ensuring comfort, structure, order, freedom from fear, and protection (Keltner & Steele, 2015:216). The concept of safety primarily involves protection and prevention of physical and psychological harm, as well as maintaining comfort and order as an expression of freedom from fear and protection (Townsend, 2015:15). Security needs include comfort within one's environment, knowledge of what to expect from people around, protection under the law from violation of rights and free access to institutions and facilities (Geyer, Mogotlane, Young, Boshoff, Chauke, Matlakala, Mokoena, Naicker & Randa, 2016:104).

The UNCRC enjoins the State to protect children and provided them with proper care for their wellbeing through legislative measures (United Nations, 1990:2). The UNCRPD also asserts the protection of children from exploitation, abuse and forced labour. Their personal health and information requires respect for their human dignity (United Nations, 2006:15). The families have great responsibility of protecting the children with ID by ensuring their wellbeing, including health care services to manage their challenging behaviours (Rahman, 2017:1737).

The UNICEF (2007:12) identified the following actions needed to protect children with disabilities at national level:

- Development of legislation and policies to prohibit maltreatment;
- Accessible services to support children with disabilities and their families;
- Development of resourced national plan of action by all countries to integrate relevant international instruments related to protection of children with disabilities;
- Establishment of local department or multisectoral ministerial coordinating committee to develop policies and monitor the implementations;
- Development of independent ombudsperson or children's committee to monitor support;

- Provision of resources, including training of staff to ensure individual support;
- Establishment and support of deinstitutionalisation programmes of children with disabilities;
- Conduct public consciousness to prevent and address discrimination of children with disabilities;
- Implement community-based support services for children and their families; and
- Involvement of disability organisations in planning and development of policies (UNICEF, 2007:12).

3.2.3 Belonging and Love Needs

The White Paper on the Rights of Persons with Disabilities (WPRPD indicates that PWID still struggle to identify themselves and develop their sense of belonging (DoSD, 2016:17). The concept of belongingness include the need for affection, group identification and companionship, and interpersonal interactions (Townsend, 2015:15). Every person has a basic need to have a relationship, a companion and acceptance by other people around them, including members of the family and the community, close friends, and professionals providing services to them (Kneisl & Trigoboff, 2013:82). Human beings need a sense of belonging and acceptance by others, irrespective of their situations, including support from close friends, relatives and community (Townsend, 2015:15). These needs form the basis for self-esteem through respect of self and others (Uysal, et al., 2017:216).

Children with ID need belongingness and love from family members (Middleton, Nicolson & O'Neil, 2017:92). Sense of belonging and love motivate the children with ID to feel valued and appreciated (Rahman, 2017:1736). Article 7 of the UNCRC indicates that every child should belong to the family, registered immediately after birth, given a name, and acquire national status to ensure their self-identity. In addition, Article 9 of the UNCRC indicates that the child has a right to live with their parents, unless subjected to judicial reviews (United Nations, 1990:3).

Article 19 of UNCRPD stresses that isolation of the children with ID and their families from the community should be prevented. This further promotes their participation, interaction and inclusion in their community (United Nations, 2006:13). Article 18 further reinforces care of the right of the children with ID by their families (United Nations, 2006:13). Locally, the Bill of Rights chapter 2 in the Constitution accentuates everyone’s right to access appropriate social assistance, secure ecologically sustainable development, economic development and belong to cultural religious beliefs (South Africa, 1996:11). In addition, all children are entitled to a name and citizenship under parental care and family environment (South Africa, 1996:11).

3.2.4 Esteem Needs

Self-esteem and self-confidence are linked to the notion of competence, recognition and gaining approval. These concepts are the basis for sound interpersonal relationships and mental health, including reduction of stress, orientation to the environment and coping skills (Kneisl & Trigoboff, 2013: 82). Furthermore, achievement of expected outcomes enables a person to feel satisfied and self-confidence of one’s ability (Townsend & Morgan, 2018:15). Every individual desires to be competent in the performance of activities that increase or boost their own self-esteem (Kneisl & Trigoboff, 2013: 82).

Self-esteem premises on the need for appreciation from others and the need for self-appreciation. The need for appreciation from others includes reputation, status and recognition. Meanwhile, the need for self-appreciation includes self-confidence, independence, success, and talents (Uys, et al., 2017:217). Parents require confidence towards their parenting skills to ensure good development and support of their children (Geyer et al., 2016:105). The self-esteem of the children is often dependent on the way their families raised them (Middleton, et al., 2017:47).

The WHO’s world report on disability posits that the negative attitudes portrayed by society towards persons with disability reduces their self-esteem desire to interact with other people (WHO, 2011:6). The UNCRPD accentuates the importance of public awareness towards persons with disability and their rights. Such awareness ensures respect and promotes society’s acceptance of the families of children with ID (United Nations, 2006:8).

3.2.5 Self-Actualisation Needs

Self-actualisation needs are at the apex of the pyramid, and are a manifestation of self-fulfilment and realisation of potential (Kneisl & Trigoboff, 2013:83). A human being feels fulfilled once the foundational or basic needs are achieved to ensure development of self-appreciation and realisation of one’s potential. Hence, knowledge and understanding are basic needs to a person’s life (Townsend, 2015:145). A person has the right to know, understand and explore his/her environment, including the basic right to information and knowledge, which result in self-actualisation and becomes crucial when other basic needs have been fulfilled to one’s contentment (Rahman, 2017:1736).

The needs of a person increase in proportion to the rate at which they are satisfied. This involves self-sufficiency, independence and the ability to appreciate the beauty of life (Uysal, et al., 2017:216). The needs and motivation theory postulates that self-actualisation is realised with the ability of the individual to reach peak experiences. At this level of needs, children with ID are encouraged to learn cognitive skills that enable them to fit into other families and the society (Rahman, 2017:1738).

It is noteworthy that accessibility to knowledge requires an individual to seek personal growth and explore other effective strategies for purposes of managing and coping with challenging experiences (Geyer, et al., 2015:107). The UNICEF (2007:21) asserts that appropriate information should be provided to persons with disability, their families, service providers and society in order to improve all services and care; while also cultivating the potential of the child to improve independently.

Human beings are inclined to feel that ‘the sky is the limit’ as a motivating factor to achieve their goals. As such, they need to be provided with services that will equip them with relevant information and skills to reach self-fulfilment (Kneisl & Trigoboff, 2013:82). Unfortunately, failure to meet lower level needs disrupts progress towards the higher-level need of self-actualisation. Motivation of individuals in their performance encourages competency towards betterment of progress (Townsend & Morgan, 2018:156). Caregivers ought to be trained in the care and support of children with ID, which is consonance with the UNICEF’s call for the promotion of the rights of children with disabilities (UNICEF, 2007:27).

The theory posits further that, as the more primitive needs are satisfied, the more psychological needs of affection and self-esteem become the primary motivators to achieve the highest need of self-actualisation (Kneisl & Trigoboff, 2013:82; Sadock, et al., 2015:181

For purposes of this study, the hierarchy of human needs propounded by Maslow was adopted as the theoretical framework to enhance understanding in the process of exploring and describing the experiences of families raising and living with intellectually challenged children and further developing concomitant strategies for their support. The strategy development model focuses on children with ID and their families as human beings. Understanding the experiences of the children and their families helped to prioritise their needs and developing concomitant interventions to enhance their support. The researcher employed the hierarchy of needs theory in an attempt to answer the study question: “What are the support needs of the families living with child with intellectual disability”?

3.3 CONCLUSION

A healthy family benefits from participating in intervention programmes to improve its members’ quality of life. Maslow’s theory has shown that human beings ought to first meet the basic human needs at the bottom of the pyramid before the apex needs at the top of the pyramid. Such a hierarchical progression ensures that there are minimal disruptions in the value chain of achievements. In the instance of this study, families of children with ID play a major role in the achievement of these children’s needs to enable growth and development. The theory provided guidance to questions of the study to assess and understand the extent of support needed by the families raising intellectually challenged children. In the context of this study, Maslow’s theory was considered relevant, based on the interstitiality of the study’s support needs orientation and the theory’s hierarchical needs focus. The next chapter (Chapter 4) describes the research methodology applied in the study.

CHAPTER FOUR: RESEARCH METHODOLOGY

CHAPTER ONE: BACKGROUND OF THE STUDY

CHAPTER TWO: REVIEW OF LITERATURE

CHAPTER THREE: THEORETICAL FRAMEWORK

CHAPTER FOUR: RESEARCH METHODOLOGY

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- 4.2. RESEARCH DESIGN
- 4.3. STUDY SETTING
- 4.4. STUDY POPULATION AND SAMPLE SELECTION
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- 4.6. DATA MANAGEMENT AND ANALYSIS
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CHAPTER FIVE: PRESENTATION AND DESCRIPTION OF THE RESEARCH FINDINGS

CHAPTER SIX: DISCUSSION OF THE QUALITATIVE FINDINGS

CHAPTER SEVEN: SUPPORT STRATEGIES OF FAMILIES LIVING WITH CHILDREN WITH INTELLECTUAL DISABILITY

CHAPTER EIGHT: CONCLUSIONS AND RECOMMENDATIONS OF THE RESEARCH STUDY

4.1 INTRODUCTION

The previous chapter presented and discussed the study's theoretical framework in the context of Maslow's theory of needs and substantiation of its foundational tenets' relevance to the study, which further enhanced the researcher's articulation and application of appropriate design and data collection methods and processes (Knobloch, 2010:2). The current chapter essentially provides details of the research methodological approaches and processes adopted in the collection and analysis of data pertinent to the investigation of the phenomenon of children with intellectual disability and concomitant support strategies adopted by their families.

Additionally, the present chapter further describes the empirical context of the study in terms of the related sampling variables. In this regard, the sampling domain is described and explained in relation to the study population; sampling criteria; sample size; and sampling strategy (Rani, 2016). Measures of trustworthiness and their application are also discussed, as well as the researcher's experiences in the field (participants' ecological environment) during the course of primary data collection.

4.2 RESEARCH DESIGN

In essence, the research design pertains to the philosophically informed plan to manage the processes and procedures guiding the research instrumentation opted for the data gathering and analysis of the study (Mouton, 2016: 44; Kumar, 2012;106). Characteristically, the philosophical premises of the study defined the extent of its conceptual paramenters, scientific orientation and methodological appraoches. In this context, the ethnographic-constructivist philosophical paradigm informed the current study, based on its participant-centredness as the pivotal domain against which the evidence was generated (Creswell, 2014:64).

4.2.1 The Qualitative Research Design Approach

The research approach is basically a plan or strategy highlighting the steps and assumptions derived from the research philosophy in order to better guide and inform the reseracher's choice of research instruments, data analysis and interpretation in relation to both the research problem and research objectives (Creswell, 2014:64; Bogdan & Biklen, 2007:24). Based largely on its ethnographically inspired philosophical orientation, the study then adopted the qualitative research design approach in order to facilitate and enhance a stakeholder-centric mode of data collection, analysis and interpretation. The latter approach was viewed as most suitable since it also enabled a more detailed exploration and description of the ID phenomenon from the participants in an unconstrained manner through focus group discussions and in-depth interviews (Gray et al., 2017:64; De Vos et al., 2014:115).

The qualitative research design approach was further advantageous for maximising the researcher's control of factors that possibly could unduly interfere in the study's desired outcomes. It further enhanced the selection of those study participants with valuable information and experiences sufficient to legitimise the sampling procedures, including the data acquisition and analysis as well (Grove et al., 2015:211). Employing the qualitative design approach further guided the researcher's planning and implementation of the study such that the probability was increased to project the findings as an accurate representation of the reality and experiences of families living with intellectually challenged children. It is the study's well considered view that its preferred qualitative approach (complemented by the explorative, descriptive and analytic elements) strengthens its contribution to an authenticated evidence base for practice on strategies to strengthen the support needs of families living with children with ID (Gray et al., 2017:253; Maree, 2014:85).

The researcher conducted the investigation in two phases. **Phase 1** focused on a participant-centric perspective of exploring and describing the shared experiences of families living with children with ID. **Phase 2** focused on a researcher-centric perspective of developing guidelines for improving the kind of support provided to families of the children living with ID.

4.2.2 Justification of the Qualitative Research Design Approach and its Adoption

This fundamentally qualitative study explored and described the support provided to families living with children with ID in the Capricorn District Municipality of Limpopo Province, South Africa. The intention of this investigation was to develop strategies to strengthen the support provided to these families. The qualitative approach enabled the researcher to explore, obtain, describe and analyse the actual words of the participants as the truthful account of their living experiences and conditions. The multi-layered meanings derived from these words (narrated statements) were the actual focal points from which deeper understanding of the participants' support needs was obtained (Grove et al., 2015:67). Consequently, support strategies of families of the children living with ID were developed from empirically supported perspectives (Gray, et al., 2017:65; Creswell, 2014:64).

Both the research objectives and their associated questions aimed at exploring, describing and understanding participants' viewpoints regarding the nature and forms of support provided to families living with intellectually challenged children (Schmidt, Schmidt & Brown, 2017:99; Maree, 2014:88). In this qualitative study, the unstructured nature of the data collection approaches (interview-based and focus group discussions) enabled a degree of flexibility and multiple data gathering strategies in the researcher's understanding of the nature of the problem being investigated. It is on the basis of such understanding that the researcher conducted the focus groups, individual in-depth interviews and behavioural observations in the very home environments where participants experienced the phenomenon being studied (Polit & Beck, 2017: 506; De Vos et al., 2014:115).

Both the exploratory and descriptive aspects were largely employed in **Phase 1** of the data collection process, in which case the emphasis was on determining the support needs of families of the children with ID. **Phase 2** focused on the development of support need strategies.

4.2.3 Exploratory Aspect of the Qualitative Research Design Approach

Exploration is concerned with finding more information, facts and insights regarding a phenomenon or state of affairs about which there is sparse knowledge (Donley & Graueholz, 2012:39). Therefore, the exploratory aspect of the qualitative research design approach provided the architectural framework regarding the researcher's intention to explore and describe the challenges of the families raising the children with ID (Polit & Beck, 2017:56). From the perspective of the researcher, quantitative data collection approaches (such as questionnaire surveys) would not suffice to capture the range of non-numerical aspects and undiluted realities of the participants; for instance, their joy, grief, attitudes and other emotions. Accordingly, the exploratory aspect of the research design typically evolved over the course of this study to reflect the realities and viewpoints of families of the children living with ID in their ecological surroundings and experiences.

In this study, the exploratory approach enhanced the researcher's intention to find more information, facts and insights regarding the experiences of the families living with children with ID to ascertain their challenges and assess the support programmes and services available to them. The researcher's understanding of this study and its processes depended largely on the reviewed literature, and further enhanced by the empirical data collection processes. In this regard, the probing strategy was applied optimally to generated responses to the point of saturation during the focus group discussions and individual in-depth interviews (Ehrlich & Joubert, 2014:356; Maree, 2014:87). As a data collection strategy, probing also provided more information concerning the family dynamics and full nature of caregiving to children with ID.

4.2.4 Descriptive Aspect of the Qualitative Research Design Approach

The descriptive aspect of this largely qualitative study premises on explaining various aspects of the investigated phenomenon as it unfolds during the different stages of the study, particularly in the empirical data gathering phase (De Vos et al., 2014:115; Babbie & Mouton, 2012:569). The researcher conducted descriptive qualitative design to accurately explain the experiences of families with children with ID that formed the basis for develop strategies to strengthen the support systems. The families were a representative sample of the population raising intellectually challenged children within their own natural environment and affordable means (Brink et al., 2018:96).

The sum total of both explorative and descriptive approaches provided the advantage of finding out more and explaining the behavioural, emotional and attitudinal characteristics of the selected families; which would otherwise be difficult to establish in a predominantly positivist-quantitative research study (Maree, 2014:68; Babbie & Mouton, 2012:569). Such 'difficulty' is presented by the demand for objectivity, which precludes the prevalence of emotional and other unquantifiable constructs in data collection (Creswell, 2014:104). Based particularly on the primary intentions of this study, the researcher considered both the exploratory and descriptive aspects of this wholly qualitative study to be appropriate; especially insofar as these approaches reduced the possible effects of limited information obtained through a singular research approach (De Vos et al., 2014:115; Kendall & Halliday, 2014:309).

4.3 STUDY SETTING

The study setting (or research site) relates to the actual physical or geographical location of the study (Rossman & Rallis, 2012:44). The study was undertaken in the Capricorn District Municipality, one of the 5 (five) major municipality spheres of local government administration of Limpopo Province. The map shown in Figure 4.1 depicts the geographic location of the Capricorn District Municipality. The other 4 (four) municipalities in the province are: Mopani, Greater Sekhukhune, Vhembe and Waterberg.

Capricorn District Municipality itself comprises of Blouberg, Lepelle-Nkumpi, Molemole, and Polokwane municipalities. The district has higher economic growth compared to other provincial districts. The province's major employment sector resides in community services and the trade sector, which consists largely of small traders whose main goods range from fruits and vegetables, to soft drinks and cosmetics. There are 30 traditional authorities in the district. The Polokwane Municipality is the province's economic hub and administrative centre, consisting of urban, township and rural areas (Capricorn District Municipality, 2017:15).

The Capricorn District's population is concentrated mostly in the Polokwane Municipality due to the attraction of possible job opportunities, better schooling and health care facilities. The researcher chose this particular municipality due to the conglomeration of people from other districts in the province, and the relative range of health care services provided.

Figure 4.1: Map of Capricorn District Municipality Administration
Source: https://municipalities.co.za/provinces/view/5/limpopo

Limpopo Province is situated in the northernmost part of South Africa and shares borders with the provinces of Gauteng to the south, Mpumalanga to the east, and North- West to the south-west. Limpopo Province also shares borders with Zimbabwe to the north, Botswana to the west, and Mozambique to the east. The province is approximately 80% rural, and covers a land mass of 125 754 km². It is the fifth largest province in South Africa, with a population of about 5.8 million representing 10.2% of the national population (DoSD, 2013:20). The province has a diverse mix of ethnicity and unique cultural heritage prominently characterised by five dominant languages: Tshivenda, Sepedi, Xitsonga, English and Afrikaans.

The province's socio-economic review and outlook for 2018/2019 indicates that the youth constitute the majority of the population, yet experienced a high unemployment rate of 19.7% in 2017 (Limpopo Provincial Treasury, 2019:23). In 2016, more than 2 (two) million people (including the youth) were deemed economically inactive in the province, and contributed to a high poverty rate of 72.4% with an income inequality gap of 0.60 Gini coefficient (Limpopo Provincial Treasury, 2019:23). In the same year (2016), the province's average life expectancy increased to 64 years, while the disability prevalence stood at 6.4% (Statistics South Africa, 2016:23).

HIV, hypertension, asthma, diabetes, mental illness, heart diseases, arthritis, epilepsy, kidney diseases, lung diseases, and cancer are some of the province's most prevalent chronic illnesses. Such a gamut of illnesses could limit the mobility of people and affect economic output and growth (Limpopo Provincial Treasury, 2019:34). The province's Department of Co-operative Governance, Human Settlement and Traditional Affairs provides households with decent dwelling. However, some families still live in informal dwellings, which are mushrooming at a disconcerting rate. There are still challenges of households without access to piped water and hygienic toilets. The scourge of poor sanitary conditions for predominantly black informal dwellers in particular, has not decreased as expected since the dawn of democracy in 1994 (Taing, 2019:535-36).

4.4 STUDY POPULATION AND SAMPLE SELECTION

This section of the chapter presents important aspects of the participants and their environment, with particular emphasis on their relevant characteristics or dynamics that shaped/ influenced the researcher's decisions and strategies to involve them in the study (Brink et al., 2018:216).

4.4.1 Population

The study population relates to the larger group of individuals or units from which the selected participants were selected. The families of the children with ID constituted the units of analysis or population in which the researcher was interested (Gray et al., 2017:329). Owing to the vulnerability of persons with ID, the researcher selected families who were available, accessible and willing to offer information concerning their support related experiences. The study population was characterised by a set of families who possessed common characteristics insofar as experiencing the challenges of living with children with ID. Furthermore, these families met the criteria for inclusion in the study (Polit & Beck, 2017:56). The core function and common denominator of these families as a representative constituency of the population was that they provided care and raised children with ID.

4.4.1.1 Population site

The population refers to a natural home environment, setting or habitat of the families living with children with ID in Capricorn District, Limpopo Province. These families were from the Mothapo, Mothiba, Dikgale, Mamabolo, Mojapelo, Moloto, Molepo, Matlala and Mphahlele tribal authorities. The inclusion of these families from multiple sites (tribal authorities and municipalities) maximised space triangulation, which was helpful to the researcher's purpose of testing cross-site consistency (Polit & Beck, 2017:563; Savin-Baden & Major, 2013:14). The use of multiple sites was beneficial for purposes of broad representability and validity of the findings regarding the families living with children with ID.

4.4.1.2 Target population

The researcher was mostly interested in family members raising the children with ID and were directly involved in their care. Such a targeted focus on specific members of the study population reflects the researcher's attempt to maximise generalisation and transferability of this study (Savin-Baden & Major, 2013:14). In this regard, the targeted population were mothers, fathers, siblings, grandparents, aunts, uncles, and guardians. The researcher found it necessary to identify key players who were directly involved in raising the children with ID and had sufficient exposure of living with the children as primary caregivers. Therefore, the targeted members were above the age of 18 years, and were able to give informed consent for their participation in the study (Grove et al., 2015:250).

4.4.1.3 Accessible population

The family members who were available, accessible and willing to share their experiences of living with children with ID, were utilised as a framework from which the sampling criteria were drawn. It is in this regard that the mothers, fathers, siblings, grandparents, aunts, uncles and guardians of the children living with ID from the target population participated in the study (Polit & Beck, 2017:329).

4.4.2 Sampling Criteria

In the context of this study, sampling criteria premises on the range of norms, criteria or standard determined by the researcher as a reference point in the selection of suitable participants (De Vos et al., 2011:73) In this study, the chosen sub-group of the targeted population were families who were directly involved in the primary caregiving, and had the experience of living and raising children suffering from ID. The mothers, fathers, siblings, grandparents, aunts, uncles, and guardians of children living with ID were eligible for inclusion in the study (Grove et al., 2015:505). Participants could either be eligible or ineligible based on the extent of homogenous (similar) or heterogeneous (dissimilar) characteristics or qualities in relation to the larger group from which they were selected (De Vos et al., 2011:73).

4.4.2.1 Eligibility/Inclusion/Eligibility criteria

The eligibility criteria involved any member of the families whose specific characteristics were their direct caregiving responsibilities and experience or exposure to children living with ID (Savin-Baden & Major, 2013:17). Based on the ID experience, the researcher's own judgement was instrumental in determining the inclusion criteria of the participants, whose primary consideration was family members whose children were above six years old or school age assuming the children have not been recently diagnosed and were emotionally ready to express their feelings (not in the study, but generally in their life circumstances). Past research illustrated how families living with children suffering from ID were vulnerable to stress, anxiety and depression (Mertens, 2015:3-4). The following considerations rendered the participants eligible:

- Participants who were members of families living with children suffering from ID;
- Participants who were directly involved as primary caregivers in the lives of children suffering from ID;
- Participants who were knowledgeable and had lived experiences concerning the research topic;
- Participants who were articulate in communication, and mentally stable;
- Participants who volunteered their participation; and
- Family members who were 18 years of age, and above.

4.4.2.2 Ineligibility/Exclusion criteria

The researcher employed a well-considered set of principles to omit or exclude potential participants who did not meet the afire-stated selection criteria. Accordingly, the following considerations rendered prospective participants to be excluded:

- Participants who showed signs of anxiety and depression;
- Participants who were not members of the families and not living with the children suffering from ID;
- Participants who were not directly involved in the care of the child suffering from ID;
- Participants who were not having knowledge and lived experience of the research topic of this study;
- Participants who were not willing to form part of the study;
- Participants who did not volunteered to participate in the research topic under study; and
- Family members below the age of 18 years.

4.4.3 Sample Size

The size of the sample was 26 family members, categorised as follows: 16 mothers, 1 grandmother, 1 father, 1 grandfather, 2 guardians (siblings), 2 uncles, and 3 aunts. All participants were close family members of the children with ID. Data saturation was the guiding principle to determine the adequacy of the sample, when new information could not be reached beyond redundancy point (Rubin & Rubin, 2012:34). The researcher's experience and interview skills contributed to sample size determination by reaching data saturation with fewer participants. The researcher tested data saturation by interviewing two more cases until no new information emerged (Polit & Beck., 2017:528; Savin-Baden & Major, 2013:14).

Table 4.1 below is an illustration of the actual number of participants (sample size) whose selection was commensurate with the criteria or standard articulated in the selection criteria above.

Table 4.1: Number of participants in relation to primary research method used

No	Data collection method	Family members	Number of participants
1	Individual interviews	Mothers	10
		Father	1
		Grandfather	1
		Aunt	1
		Uncle	2
		Sub-total	**15**
2	Focus group discussions (FGDs)	Mothers	6
		Grandmother	1
		Guardian	2
		Aunt	2
		Sub-total	**11**
	Total Participants		**26**

The purposive selection of participants and multiple interviews collaboratively contributed to adequacy of the sample size in which pertinent data on the experiences of the families were fully explored (Polit & Beck, 2017:497; Brink et al., 2018:128).

4.4.4 Sampling Methods

Non-probability purposive snowball sampling procedure selected the families to participate in the study. The purpose of initiating these multi-sampling techniques enabled the researcher to select participants with experience and knowledge of living with the children with ID and willing to participate in the study.

4.4.4.1 Non-probability purposive sampling

Both the non-probability purposive sampling and snowball sampling techniques were utilised for the recruitment and consequent selection of only families who were knowledgeable and experienced in raising children with ID The aim of selecting this category participants was informed by their ability to provide rich and detailed information regarding children living with ID.

The reason for the purposive/ judgement sampling was influenced by the researchers' intention to explore, describe and analyse the support provided to the families of children with ID that benefited this study (Grove et al., 2015:270; Kumar, 2012:116). Accordingly, purposive sampling was deemed relevant, based on the researcher's own judgement of the prospective participants' suitability (Brink et al., 2018:124). In addition, this sampling method enabled the researcher the latitude to conduct in-depth interviews with only the 'fit-for-purpose' families in terms of the criteria sought by the researcher (Creswell, 2014:189).

4.4.4.1.1 Snowball sampling

The researcher employed snowball sampling to complement the purposive sampling strategy. Snowball sampling refers to a network-based approach to recruiting participants for involvement in the study (Kumar, 2012:190). In such instances, the researcher consults a few participants, who then use their own networks to recruit other participants who will then be subjected to the judgement of the researcher for suitability or otherwise to participate in the study.

The vulnerability of the families of children living with ID resulted in the researcher approaching a few families who then introduced other families. The initial set of families were able to inform the researcher about other families they knew or met during community gatherings, school meetings and functions (Brink et al., 2018:127). Through this approach, the researcher was also able to identify even the families not known at nearby health facilities, centres or schools. These families were not averse to participating, and fulfilled the sampling inclusion criteria.

4.5 DATA COLLECTION

The study employed in-depth individual and focus group discussions, complemented with observational field notes to maximise the data collection process and its anticipated outcomes (Saldana & Omasta, 2018:272; Thomas & Magilvy, 2011:151). These methods were field-based and conducted in the natural environment of the families of children with ID. The nature of the problem and the research question guiding this study determined these semi-structured interviews (Grove et al., 2015:83). Whereas Table 4.1 reflected the overall number of participants in relation to each primary research method used (i.e. individual interviews and focus group discussions), Table 4.2 below depicts the variability of the selected participants' demographic characteristics in terms of their age, marital status, level of education, religious affiliation and occupation.

Table 4.2: Demographic information of participants

Participants	Age	Marital status	Relationship to the child	Level of Education	Religion	**Occupation**
P1	44	Separated	Mother	Grade 12	Christian	Employed
P2	19	Single	Sibling	Grade 11	Christian	Schooling
P3	41	Single	Mother	Grade 11	Christian	Employed
P4	51	Married	Mother	Grade 12	Christian	Unemployed
P5	63	Widowed	Mother	Grade 6	Christian	Pensioner
P6	42	Single	Mother	Grade 7	None	Unemployed
P7	40	Separated	Mother	Grade 10	None	Employed
P8	53	Married	Mother	Grade 9	Christian	Unemployed
P9	42	Single	Aunt	Degree	Christian	Unemployed
P10	45	Married	Mother	Grade 12	Christian	Unemployed
P11	27	Married	Sibling	Grade 12	Christian	Unemployed
P12	43	Single	Mother	Grade 10	Christian	Unemployed
P13	35	Married	Mother	Grade 12	Christian	Employed
P14	42	Single	Aunt	Grade 11	Christian	Unemployed
P15	40	Divorced	Mother	Grade 12	Christian	Unemployed
P16	54	Married	Mother	Grade 6	Christian	Unemployed
P17	66	Married	Grandmother	Grade 4	None	Pensioner
P18	50	Single	Mother	Grade 10	Christian	Unemployed
P19	36	Single	Mother	Grade 12	Christian	Unemployed
P20	47	Divorced	Mother	Grade 11	Christian	Unemployed
P21	32	Single	Mother	Diploma	Christian	Unemployed
P22	39	Divorced	Aunt	Grade 11	Christian	Unemployed
P23	55	Married	Father	Diploma	Christian	Employed
P24	67	Widowed	Grandfather	Grade 7	Christian	Pensioner
P25	31	Married	Uncle	Grade 12	Christian	Employed
P26	24	Single	Uncle	Diploma	Christian	Unemployed

The youngest participants was 19 years old, and the oldest was 67 years old. It is worth stating that these age categories were for those participants living with, or directly cared for children with ID. Whereas Table 4.2 above focused on the families and caregivers, Table 4.3 below specifically focuses on the children living with ID.

Table 4.3: Demographic data of the children with ID

Participants' child (C)	Age of the child	Gender	Educational status	Problems	Disability grant
C1	9	Male	Day care	Speech	Yes
C2	16	Male	Not schooling	Dental	Yes
C3	17	Female	Not schooling	Speech	Yes
C4	16	Male	Not schooling	Speech	Yes
C5	17	Female	Not schooling	Dental	Yes
C6	14	Male	Not schooling	Epilepsy	Yes
C7	17	Male	Not schooling	Speech	Yes
C8	16	Male	Schooling	Hearing	Yes
C9	16	Female	Not schooling	Speech	Yes
C10	10	Male	Schooling	Speech	Yes
C11	11	Male	Not schooling	Microcephaly	Yes
C12	10	Male	Not schooling	Dental	Yes
C13	7	Male	Not schooling	Speech	Yes
C14	12	Male	Day care	Dental	Yes
C15	8	Female	Day care	Speech	Yes
C16	15	Male	Not schooling	Hydrocephalus	Yes
C17	14	Male	Not schooling	Epilepsy	Yes
C18	17	Male	Not schooling	Hearing	Yes
C19	16	Female	Not schooling	Dental	Yes
C20	12	Male	Day care	Epilepsy	Yes
C21	11	Male	Day care	Dental	Yes
C22	17	Male	Not schooling	Epilepsy	Yes
C23	14	Female	Schooling	Speech	Yes
C24	16	Female	Schooling	None	Yes
C25	12	Male	Schooling	Dental	Yes
C26	9	Male	Not schooling	Speech	Yes

Extrapolated from Table 4.3 above is that the youngest child with ID was 9 (nine) years, with the oldest 17 years of age. Table 4.4 below shows household-related information of the families living with intellectually challenged children. The table information was discussed in detailed in the next chapter 5.

Table 4.4: Participants' households' types

Type of family	Number of families
Nuclear	7
Female headed	11
Three generation	4
Skip generation	2
Child-headed	1
Polygynous	1
Total	**26**

4.5.1 Study Piloting

A pilot study was undertaken prior to actual data collection with the utilisation of one focus group discussion involving 4 (four) families, and individual in-depth interviews with 2 (two) families. The pilot study assisted the researcher's refinement of appropriate interviewing and recording skills, and to further test the nature and suitability of the interview questions. Following the piloting process (Rubin & Rubin, 2012:38), the researcher was able to modify the interview guides to ensure effectiveness and relevance to both the research problem and objectives of the study (Grove et al., 2015:509).

The researcher further discussed the post-piloting interview questions with the experts in ID to evaluate their structure, content and suitability to collect relevant quality information (De Vos et al., 2014:395). For instance, duplicated questions were removed, ambiguous questions were clarified for better understanding. Additional questions were included to develop the final version of the interview guide (Thomas & Magilvy, 2011:154).

4.5.2 Recruitment of Participants

The researcher recruited the families through their clinic records, day care centres for children with ID, participating families and the community health care workers. Some of the families further referred the researcher to the families they knew through their networks; hence, the snowball sampling effect. The day care centres staff and the community health care workers assisted the researcher to locate the homes of the participants. Appointments were made telephonically with the families to confirm the date, time and venues of the interviews at their convenience.

4.5.3 Individual In-depth Interviews

Accruing from the pretested (piloted) interview and focus group questions, the researcher then developed an interview guide for both the actual individual in-depth interviews and focus group discussions. The reviewed literature guided the development of the interview guide in respect of the scope/range of information needed to explore the experiences of families raising the children with ID. The interview guide questions were logically sequenced from the general to the specific (Polit & Beck, 2017:510; Walliman, 2015:83). The interview guide was designed in a semi-structured format to allow the element of comparability of information from different participants (Saldanha & Omasta, 2018:199).

Open-ended non-judgemental questions allowed participants to share more closely in the direction of the study and were able to introduce new information to the researcher.

The first part of the interview guide outlined the purpose and objectives of the study and consent to participate in the study. Section A of the interview guide premised on questions to gather the socio-biographical information of all participants. Section B focused on open-ended questions, while Section C focused on focus group discussions to explore the experiences and challenges of raising children with ID. The interview guide was translated from English into Sepedi, which was the dominant vernacular in the Capricorn District Municipality. The researcher understood all languages spoken in Limpopo Province.

4.5.3.1 Administration of the individual in-depth interviews

Sixteen (16) individual in-depths interviews were conducted to facilitate the exploration and description of the participants’ experiences concerning the care and support they allocated to children with ID. The interviews benefited the study by providing a line of enquiry that enabled the researcher to ask predetermined questions to describe the experiences of support provided to the families raising the children with ID (Maree, 2014:87). In selecting this approach, the researcher afforded the participants’ free engagement, knowledge sharing and lived experiences in conducive and unconstrained environs that also allowed for probing and data saturation (Walliman, 2015:83).

During these interviews, the researcher introduced herself and explained the purpose of the interviews and expected nature of participation (Brink et al., 2018:144). The interviews were conducted at the participants’ convenient time and place. For instance, the in-depth face-to-face interviews took place at the participants’ homes where they felt comfortable to express their feelings and experiences about caring for, and raising children with ID. Each individual gave permission for inclusion in the study by signing a consent form with a witness. The interview schedule guided the interviews. The researcher obtained verbal consent from the participants concerning the use of an audio recorder as a tool for obtaining raw and original data (Walliman, 2015:83).

The main interview question was premised on a description of the families’ or caregivers’ support needs and experiences of living with intellectually disabled children. Probing and follow-up questions were asked to obtain more information and clearer responses (Kirby et al., 2015; 33; De Vos et al., 2014:352).

The interview guide directed the follow-up questioning process in a structured manner (Polit & Beck, 2017:510). The follow-up probing by the researcher enabled the participants to provide a more detailed picture of their experiences concerning the support they received to mitigate the challenges of living with the children with ID (De Vos et al., 2014:352; Maree, 2014:96). A relaxed face-to-face communication with families throughout the interviews encouraged participants to express their heartfelt feelings.

Each individual in-depth interview lasted for more than 60 minutes, largely due to the sensitivity of the topic. The researcher ensured that the nature of questioning did not infringe on the participants human dignity, which encourage participants to confidently share more information on those issues requiring further clarification by the researcher (Walliman, 2015:91; Maree, 2014:87).

4.5.4 Focus Group Discussions (FGDs)

The FGD was selected as a means of triangulating information obtained from the preceding individual in-depth interviews. The researcher conducted one FGD comprising of women representing ten families of different experiences, geographical areas (tribal authorities) and socio-economic backgrounds. The males were excluded in FGD to give participants the opportunity to express their feelings freely. The family's selection was based on the requirement to meet the study's inclusion criteria. The researcher was motivated to include the focus group with the knowledge that they were knowledgeable and representative of families who experienced the challenges of each family member.

The benefits of conducting the FGD with the families was that it provided rich information through discussions and sharing of the complex experiences of raising children with ID. The researcher was able to explore their historical backgrounds and challenges of living with children with ID (Grove et al., 2015:85; Kirby et al., 2015; 33).

Most participants informed were able to attend the FGD, and two more were recruited through the process of snowballing by their friends. Participants were reminded a day before the group discussions. The researcher provided transport to some of the participants from different villages to the FGD venues. The researcher reimbursed the costs of those who managed to use public transport to the venue, and further transported them back home. One family member volunteered to provide the venue for the FGD as she desired to be part of the group but could not move out of the house due to the responsibility of caring for her grandchild with ID. The veranda at the back of the house was used as the FGD venue. The house was between two empty sites and that ensured privacy and confidentiality of participants. Similar to the interviews, the researcher indicated the purpose of the interviews and afforded the families the opportunity raise their concerns.

The researcher assisted some participants to complete the individual questionnaires requiring socio-demographic data. The researcher established harmonious relationship with family members by welcoming them in a friendly non-judgemental way in order to encourage their participation. The background information and purpose of the study were made known to the families to enable their full understanding of the process (Mertens, 2015:4. The researcher also read the informed consent requirement to the participants in both English and Sepedi, and also explained ethical aspects relating to confidentiality, privacy and anonymity. Verbal consent of the FGD participants was obtained for the use of an audio recorder. Similar to the procedure followed for the interviews, all participants signed the informed consent form with a witness. Ground rules set by both the researcher and participants, ensured smooth running of the discussion (Polit & Beck, 2017:511).

The researcher explored the topic by asking open-ended questions and avoided rephrasing the participants' answers so as to prevent bias and prejudice (Muller & Bester, 2017:43). The homogeneity of the composition of the family members encouraged the focus group to share sensitive information on their experiences and challenges. Owing to vulnerability of the group as well, the researcher was cautious of any indications of emotional responses by focus group members. To this end, participants were allowed to explain their views in detail with no interruptions. The FGD lasted for four hours. Overall, the complementary role of the FGD maximised the adequacy of representation of the families of the children living with ID in respect of the dependability, credibility and generalisation of the study (Silverman, 2017:68).

4.5.5 Observational Field Notes

Observational field notes are described as the researcher's broader, analytical and interpretative representation and understanding of the field-based observations that would not have been captured on the audio recorder during both the interviews and FGDs (Marshall & Rossman, 2016:46). The researcher used field notes during data collection and analysis to enhance the validity and reliability of the findings. The researcher noted and documented pertinent information such as the participants' emotional and psychological state and attitude to questions posed to them. It was not possible to rely only on one's memory for proceedings of all interviews and the focus group (De Vos et al., 2014:377). The researcher further observed that participants were joyful for most parts to be part of the study. The families were more welcoming and willing to provide the researcher with more information. All participants were actively involved during the interviews. It also emerged that the participants were using the empirical data collection process as an avenue to vent their concerns after which they felt relieved.

4.5.5.1 Field experiences and challenges

Some of the family members who initially agreed to form part of the study, later declined at the last hour under the pretext that they were busy. The researcher could not find verifiable reasons for their sudden rescission. However, some delegated their family members to represent them. In some instance, the researcher conducted one individual in-depth interview at a participant's workplace (in the office) as she felt uncomfortable in the presence of her husband at home. One particularly noticeable observation was that some of the families of physically challenged children (without any intellectual challenges) could not understand their exclusion from the study.

4.6 DATA MANAGEMENT AND ANALYSIS

4.6.1 Data management

Data management precedes data analysis, although both processes can also be performed concurrently, depending on the researcher's expertise in this regard (Babbie & Mouton, 2012:119). In essence, data management relates to the systematic process of preserving and maintaining data in its original or raw state before it is converted into thematic categories of meaningful statements that eventually become the evidence base of the study (Flick, 2014:38). The management of collected data ensures its adequate preparation and processing before the actual phase of synthesising and analysing the self-same data.

The researcher collected data for this study for a period of six months. For its management, the audio recorded data was kept safely and analysed simultaneously to ensure that no data were lost (Aneshensel, 2015:1). The researcher transcribed both the interviews and FGDs on Excel sheets, organised the field notes and fully analysed the data to generate holistic understanding of the experiences of the families living with intellectually challenged children. Data was then shared with the researcher's academic supervisor to confirm the themes, categories and sub-categories for quality analysis (Botma, Greeff, Mulaudzi & Wright, 2010:221). Thereafter, data was labelled by date and all copies and materials, including field notes, audio recordings, questionnaires and backup copies were protected and kept in a container in a safe place known to the researcher only (De Vos et al. 2014:408; Botma et al., 2010:22).

The Protection of Personal Information Act (No. 4 of 2013) prescribes that personal information should be secured with integrity and confidentiality under the control of a responsible party in order to prevent loss, damage, processing, destruction or unlawful access (South Africa, 2013:32). The researcher should ensure that data on video, audio or paper are stored in locked fireproof cabinets for at least five to ten years or three years if for study purposes (Moule & Goodman, 2014:69).

4.6.2 Data Analysis

Data analysis is the post-data management process during which the preserved or uncontaminated raw data is systematically and procedurally organised according to individual or global themes and sub-categories for purposes of providing structure and accurate meaning to serve as evidence of the study (Flick, 2014:36; Botma et al., 2010:221). The data analysis process also involves making sense of text and images to generate ideas based on the data collected (Polit & Beck, 2017:306; Botma et al., 2010:221).

The researcher analysed data concurrently with the data collection process, with the Atlas. Ti 8 computer programme used to confirm the findings. Data were analysed in a continuous, emergent, reiterative non-linear process, which allowed for ongoing reflection, logical questioning and note-taking throughout the study (LoBiondo-Wood & Haber, 2014:124; Creswell, 2014:184). The researcher chose the Atlas. Ti computer programme for a more systematic approach to facilitate text analysis of the observational field notes and interpretation of data. The analytic process included selecting, coding, annotating and comparing noteworthy segments. The computer programme was particularly useful in the development and coding of themes and categories that were consistent with the participants' information. The computer programme was further useful for handling multiple and overlapping codes without losing the context (Henning, van Rensburg & Smit, 2013:6). The steps outlined below constituted the pivotal means by which data was processed and eventually analysed:

4.6.2.1 Transcripts

The researcher listened to the audio recorded interviews and transcribed each into typed Excel sheet text. The researcher then reviewed transcribed data and removed any information that could link the participants to any aspect of the data (Ehrlich & Joubert, 2014:105).

4.6.2.2 Coding

The researcher familiarised herself with the data by re-reading the transcripts in conjunction with written field notes (Rubin & Rubin, 2012:5). Various codes were allocated to participants and themes to which each of the participants was associated. The researcher further uploaded the transcripts to the Atlas. Ti qualitative data analysis software for a systematic and time efficient approach. Codes were assigned from an alpha-numeric coding list with the assistance of a coding manager.

4.6.2.3 Thematic categorisation

The researcher involved and immersed self in the data and identified codes with the assistance of the computer programme (Babbie & Mouton, 2012:86). Similar codes were arranged according to emerging 'families' of individual and global themes and associated categories and sub-categories. The interpretation of identified themes and emerging categories and sub-categories was performed in tandem with existing literature (Babbie & Mouton, 2012:86.

4.6.2.5 Patterns/Trends

The researcher employed content analysis of the themes, categories and related sub-categories from frequently occurring trends and patterns from the participants' narrative statements. Data were duly categorised and compared, including examination of any connections, regularities, variations and peculiarities (Rossman & Rallis, 2012:51).

4.6.2.6 Discussion

The researcher studied and examined correlations or relationships between different categories to develop a framework of clearer ideas on more complex variables and themes Marshall & Rossman, 2016:119). Information was summarised into meaningful findings, presented into thick descriptions as well as quotes from the participants to demonstrate their authenticated voice in the context of supporting literature-based evidence (Henning et al., 2013:7). Figures and tables were utilised to provide a visualised context of the study's findings.

4.7 PHASE 2: DEVELOPMENT OF STRATEGIES TO SUPPORT FAMILIES OF CHILDREN LIVING WITH ID

Phase 2 of the inquiry entailed the development of strategies to fulfil the core goal of the study, which is to develop strategies to support families living with children suffering from intellectual disability. The strategy development process evolved from synthesising and analysing the data and findings of the study in Phase I as articulated in sub-section 4.6.2. Themes and categories identified in these findings provided evidence to develop proposed strategies to support and strengthen the families living with children with ID. The purpose, scope and objectives of strategy development outlined the guiding principles of the developed strategies as finally articulated and presented in the context of strategy statements in Chapter 7.

The next section focuses of the chapter focuses on the measures taken to ensure the trustworthiness of the study.

4.8 MEASURES TO ESTABLISH AND MAINTAIN TRUSTWORTHINESS

This qualitative study applied the trustworthiness standard to evaluate the strength and quality and to ensure rigour of the study, as well as determining the degree of confidence in the findings (Grove et al., 2015:392). The quality and trustworthiness of the research was assessed with reference to the dependability, credibility, transferability, authenticity and conformability framework (LoBiondo-Wood & Haber, 2014:134; Polit & Beck, 2017:559).

4.8.1 Credibility

The researcher employed credibility to ensure confidence and trust in the truthfulness of the data, its interpretations and understanding of context of the study (Polit & Beck, 2017:557). Credibility also ensured the enhancement of believability of the study findings to the external readers. The researcher allowed participants to assess the veracity of the findings, whether they accurately represented their views. In this regard, prolonged engagement, persistent observation, triangulation, peer debriefing, member checking and referral adequacy were applied as confidence measure to demonstrate the true shared experiences of families of children with ID (Grove et al., 2015:392; LoBiondo-Wood & Haber, 2014:126).

4.8.1.1 Prolonged engagement

The researcher ensured credibility of the findings by spending sufficient time in the field engaging with participants, which facilitated collection of rich data and better understanding of the challenges of families living with children with ID (Brink et al., 2018:158). The researcher further spent more time with participants in their homes to build trust, rapport and encouraging freedom to express their experiences. Consequently, this enhanced testing for distortions and misinformation to ensure saturation of key variables pertaining to the narrated statements as the basis for the findings (Polit & Beck, 2017:561).

The time that the researcher spent in contact with the families was beneficial to them as an opportunity to clarify questions and further understanding of their worldviews (Botma et al., 2010:126). Each individual in-depths interview lasted for more than 60 minutes to allow participants adequate time to share and express their experiences.

4.8.1.2 Triangulation

Triangulation was employed in order to obtain truthful accounts and information from different participant perspectives relating to the experience of living with, and caring for children with ID (Ehrlich & Joubert, 2014:488). Data triangulation was employed with the use of interviews, in-depth individual and focus group discussions, observing participants' behaviour in their natural home settings; as well as comprehensive field notes to describe the study environment in its entirety (Polit & Beck, 2017:565). Furthermore, different family members, including parents, siblings, grandparents, guardians, uncles and aunts were involved in the study to provide a consolidated and accurate representation of reality from the participants' perspectives (Grove et al., 2015:513; Brink et al., 2018:85).

Analysis triangulation was employed for both the qualitative and quantitative aspects of the collected data in this predominantly qualitative research. The quantitative aspects of the triangulated approach related mainly to the biographic information of the participants (Creswell 2014:201). The researcher viewed all the information, familiarised, internalised and organised data into comprehensive themes relating to the support provided to families of children with ID. Additionally, the researcher consulted different literature sources to consolidate the data and method triangulation process.

4.8.1.3 Peer debriefing

The researcher conducted debriefing sessions with colleagues to obtain their knowledgeable views and insights concerning steps and decisions taken throughout the research process (Silverman, 2017:71). The peers were professional nurse lecturers who facilitate and teach Intellectual Disability content to student nurses. This process allowed the researcher to discuss the written summaries of the data, categories and themes emerging from the study. Furthermore, the peer advice enhanced the reduction of researcher bias in the preparation of the final research report (Babbie & Mouton, 2012:302).

4.8.1.4 Member checking

The researcher provided oral feedback to the families on emerging study interpretations (Babbie & Mouton, 2012:302). In addition, the researcher involved the participants by presenting the final report back to the participants to correct any possible errors or misrepresentations by the researcher in her findings. In this regard, the member checking process ensured the accuracy of the findings and overall adequacy of data. Most importantly, member checking was advantageous for ensuring that data-related conclusions were commensurate with, and truthful to discussions emanating from the views and experiences of living with children with ID (Flick, 2014:39).

4.8.1.5 Referential adequacy

Referential adequacy pertains to the identification and incorporation of particular aspects of data as part of the larger analytic framework of the study (Brink et al., 2018:218). In this regard, the researcher relied on the participants' informed consent as the primary reference point for the adequacy of the required agreement for the utilisation of audio-recording equipment for data storage and preservation of critical information relating to the experience of living with intellectually challenged children. In addition, field notes were not merely taken for archival purposes, but were incorporated into the evidentiary framework of the study's triangulation trajectory.

4.8.2 Dependability

Dependability ensured the provision of approximately similar evidence with different participants in a different research context, but using the same methods as in the original study (Brink et al., 2018:217). Implementation of study methods and data collection processes and procedures were implemented comprehensively to enable repeatability for future research (LoBiondo-Wood & Haber, 2014:136). The researcher ensured the findings' dependability by asking the same questions among all participants during the various stages of the multiple data collection methods. The second coding of data after three months ensured there was a degree of repeatability without reference to the first coded categories and themes.

4.8.2.1 Reflexivity

In this qualitative research, the researcher employed reflexivity to reduce personal bias and judgemental views about the true state and honest on perceptions of human lived experiences of families living with children with ID (Burns & Grove, 2017:256). This process assisted the researcher to focus on self-critical reflection, analysing and scrutinising personal values that could interfere with data collection and interpretation.

The aspect of reflexivity could be viewed as a research *sine qua non*, considering that the researcher could have been influenced by the fact that she was the creator of the research questions and personal facilitator of the analytic process itself. Also, the researcher's qualifications in research and experience as ID lecturer necessitated that reflexivity and critical self-monitoring and introspection be applied throughout the study - especially during the empiric al data collection and analysis stages (Polit & Beck, 2017:570).

4.8.2.2 Bracketing

The bracketing technique was implemented to identify and set aside the researcher's preconceived ideas, opinions and beliefs about the experience of living with intellectually challenged children (Aneshensel, 2015:2). The researcher intentionally wrote her experiences, thoughts and assumptions that may interfere with the data collection and analysis process in order to preclude any misinterpretation of the family experiences of living with children with ID by the researcher. This allowed the researcher to approach the data collection and analysis processes in an objective manner with the assistance of the audio recorder to capture the verbatim responses and experiences of the participants (Grove et al., 2015:501; Polit & Beck, 2017:495).

4.8.3 Confirmability

The researcher ensured reflection of participants' undiluted voices of experiences relating to living with, and caring for children with ID. To this end, the researcher avoided any preconceived and ulterior motivations, biases or perceptions that could influence the research findings prejudicially. Raw data was compiled in relation to themes, categories, and subcategories with the assistance of Atlas in this study. Ti computerised programme. The researcher's academic supervisor assisted by confirming the appropriateness and relevance of the themes, categories and sub-categories. This further assured that the findings, conclusions and recommendations were supported by collected data and that there was internal agreement between the researcher`s interpretation and the actual evidence (Polit & Beck, 2014:1750; Brink et al., 2018:216).

4.8.4 Transferability

The researcher has identified and described sufficient specific information regarding the support needs of different families from different locations who represented families raising children with ID in the Capricorn Municipality District. The researcher has further provided background information with detailed description to establish the context of the study to allow readers to make informed and evidence-based comparisons. However, the researcher did not necessarily agree to the view that knowledge gained from one context will necessary be relevant to other, or the same context in another period. Purposive sampling of participants enhanced the collection of rich findings, which are not necessarily generalisable, but specific to the Capricorn District Municipality (Brink et al., 2012; LoBiondo-Wood & Haber, 2014).

4.8.5 Authenticity

The researcher provided a true report of the experiences of families living with the children with ID. Authenticity enabled the researcher to give a fair, faithful, honest, and balanced account from the viewpoints of the families and individuals who lived and experienced the challenges associated with children living with ID in their everyday lives. The researcher's continuous attempts to preclude prejudice and bias is further proof of the authenticity of the findings as true reflection of the participants' real-world experiences. However, such authenticity also invites readers to share experiences regarding support of families living with children with ID (Polit & Beck, 2017:560).

4.8 CONCLUSION

This chapter provided details of the preferred research design and methodology applied in the study. A qualitative, exploratory and descriptive research methodology was opted for in collecting data from members of families living with children with ID. It is worth noting that the affected children themselves were not directly involved in the data collection, but were represented by individual family members. Focus group discussion and individual in-depth interviews constituted the primary means by which rich data was collected from the study's sampled heterogeneous stakeholder constituencies. Data management and analysis strategies were also elaborated in this chapter. Given the sensitivities on ID, clearly defined approaches and considerations were adhered to maintain both the human dignity of the participants and trustworthiness of the findings. The next chapter discusses the findings and interprets the results of the study.

CHAPTER FIVE: PRESENTATION AND DESCRIPTION OF THE RESEARCH FINDINGS

CHAPTER ONE: BACKGROUND OF THE STUDY

CHAPTER TWO: REVIEW OF LITERATURE

CHAPTER THREE: THEORETICAL FRAMEWORK

CHAPTER FOUR: RESEARCH METHODOLOGY

CHAPTER FIVE: PRESENTATION AND DESCRIPTION OF THE RESEARCH FINDINGS

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- 5.2. SOCIO-DEMOGRAPHIC INFORMATION OF PARTICIPANTS
- 5.3. RESEARCH FINDINGS
- 5.3.1 THE NEED FOR INFORMATIONAL SUPPORT
- 5.3.2 THE NEED FOR PROFESSIONAL SUPPORT
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- 5.3.4 THE NEED FOR SOCIAL SUPPORT
- 5.3.5 THE NEED FOR FINANCIAL SUPPORT
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CHAPTER SIX: DISCUSSION OF THE QUALITATIVE FINDINGS

CHAPTER SEVEN: SUPPORT STRAGTEGIES OF FAMILIES LIVING WITH CHILDREN WITH INTELLECTUAL DISABILITY

CHAPTER EIGHT: CONCLUSIONS AND RECOMMENDATIONS OF THE RESEARCH STUDY

5.1 INTRODUCTION

The preceding chapter basically presented the research methodology of the study. The purpose of the current chapter, on the other hand, is to present the study's findings, which essentially serve as the evidence of the study and demonstrates the extent to which the self-same study has achieved its objectives as stated in Section 1.5 (pp. 10-11) (Henning et al., 2013:16; Thomas & Magilvy, 2011:152). The chapter further provides the generated evidence in accordance with the pertinent themes and related categories derived from the analysed data of the participants' verbatim statements. Diagrammatic visuals that include charts, tables and figures are used in this chapter to complement the prosaic discussions and thematically analysed narrative statements of the participants which served as the core of the study's anticipated evidence (Botma et al., 2010:42).

For purposes of clarity and logical presentation, the chapter is basically delineated into two focal areas of discussion, namely, the socio-demographic information of the participants and the research findings themselves as the product of the thematically categorised statements of the 26 participants who eventually participated in the study. As a result of the copious information and data obtained from these participants, the section on the research findings is structured according to the 7 (seven) main themes and their specific categories and sub-categories. These themes logically address the support needs of families living with, and caring for children born with intellectual disability in Capricorn District, Limpopo Province. It is worth stating that the generated evidence and themes are reflective of the authentic views of the participants concerning the support they need to cope with challenges associated with living with, and caring for children born with ID.

The researcher merged the results of the participants' biographic information and the collected qualitative data from both focus and individual interviews as part of the discussion, analysis and interpretation of various themes in relation to the study's objectives (Saldana & Omasta, 2018:277). The following research objectives formed the basis for this qualitative study as outlined in Chapter 1:

- To describe the demographic profile of children living with intellectual disability in Capricorn district of Limpopo Province.
- To explore and describe the challenges experienced by families living with ID children.

- To assess the existing support programmes and services provided to families living with ID children.
- To develop the support strategies to strengthen the families living with children who have ID.

5.2 SOCIO-DEMOGRAPHIC INFORMATION OF PARTICIPANTS

The participants' socio-demographic information included variables such as their age, gender, marital status, relationship to the child with ID, educational qualifications, employment details and religion affiliation. The profile data of the children with ID was also included.

5.2.1 Composition of the Sample

The sample consisted of 26 participants who represented the families living with, and caring for the intellectually challenged children in the Capricorn District, Limpopo Province. The results showed that 58% (n=15) of the participants were mothers of the children, fathers 4% (n=1), aunts 11% (n=3), sisters 7% (n=2), uncles 8% (n=2), grandfather 4% (n=1), and grandmothers 8% (n=2). These findings indicate that the caring responsibility of the children with ID lies mostly with the mothers. The aunts were from the maternal side of the children, who took caring responsibilities to assist the mothers who were at work. The uncles were also from the maternal side of the children, while the grandparents were from the three and skip generation families.

5.2.2 Participants' Age Distribution

Figure 5.1 below depicts the age distribution of the participants in this study. The age group was included to show the responsibilities taken by family members to care for the children with ID. The dominant age group of participants was between 19 and 66 years of age. The findings indicated that 39% (n=10) were between the ages of 39 and 48 years, and were middle age group adults between the ages of 49 and 58 years (19%, n=5); those between 29 and 38 years at 15% (n=4); 38 and 48 years at 15% (n=4); and 19 and 28 years of age at 12% (n=3). The caregivers of the children were in the middle age group and employable in the formal economic sectors, but preferred to care for the children with ID.

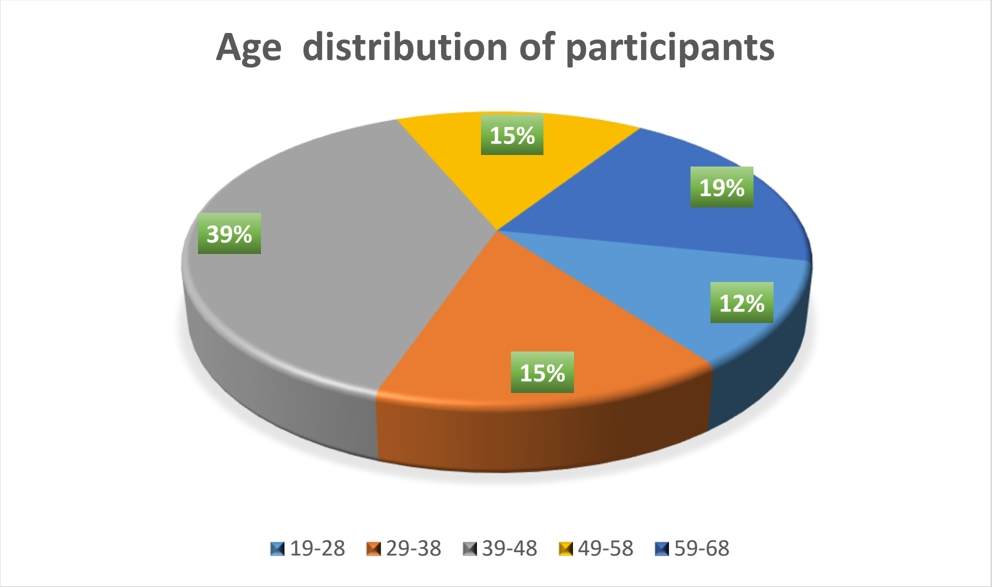

Figure 5.1: Age distribution of participants (N=26)

5.2.3 Participants' Gender

Most of the participants representing the families were females at 85% (n=22), and males at 15% (n=4). The females represented mothers, aunts, sisters and grandmothers, while males represented fathers, uncles and grandfathers. Males (fathers) who did not participate in the study (stereotypically) gave the reason that the mothers were relevant as participants because they knew all family members and also took care of the whole family. This highlights the fact that females were the primary caregivers responsible for the growth and development of the children. The stereotypical perception and feminist character female-dominated child care promotes the perception that only women should take care of children. Furthermore, this is evident of the patriarchal practices and perspectives of males who are predominantly viewed as heads of families who should not be tied to providing care for their children with ID in the same manner as their female counterparts.

5.2.4 Participants' Marital Status

Figure 5.2 below displays the marital status of participants. The marital status was included to determine stability of partners in supporting each other in the care of their child with ID.

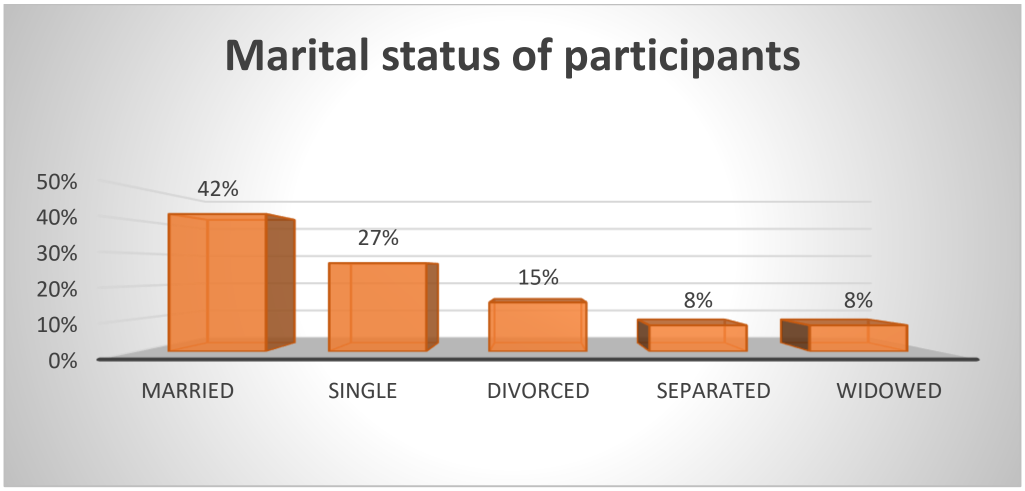

Figure 5.2: Marital status of participants (N=26)

The findings from the above figure show that 42% (n-=11) of participants were single, 27% (n=7) were married, 15% (n=4) were divorced, 8% (n=2) were separated from their partners; and 8% (n=2) were widowed. The separation and divorce rates add to families without partners, which increased the number of families with one parent.

The information above highlighted the fact that most mothers were single parents, and that most families were female-headed households. Furthermore, the impact of female-headed households is that most children grew with absent fathers, and their mothers assumed breadwinner responsibilities. Some of the separation and divorce happened after the birth of the children with disability. However, those who were divorced or separated were not receiving adequate financial support from the fathers of the children, which resulted in over-dependence on social grants.

5.2.5 Participants' Relationship to the Child

Figure 5.3 below displays the relationship of participants to the children with ID. The relationship of participants was included in order to determine the extent and nature of caregiving to the children with ID. The results show that 58% (n=15) of the participants were mothers of the children, fathers at 4% (n=1), aunts were 11% (n=3), sisters at 7% (n=2); while uncles were at 8% (n=2), grandfather at 4% (n=1), and grandmothers at 8% (n=2). Extrapolated from these findings is that most of the caregivers were mothers who shouldered the greatest responsibility of caring for the children with ID. This highlighted that the mothers took the lead in taking care of the families more than other members did.

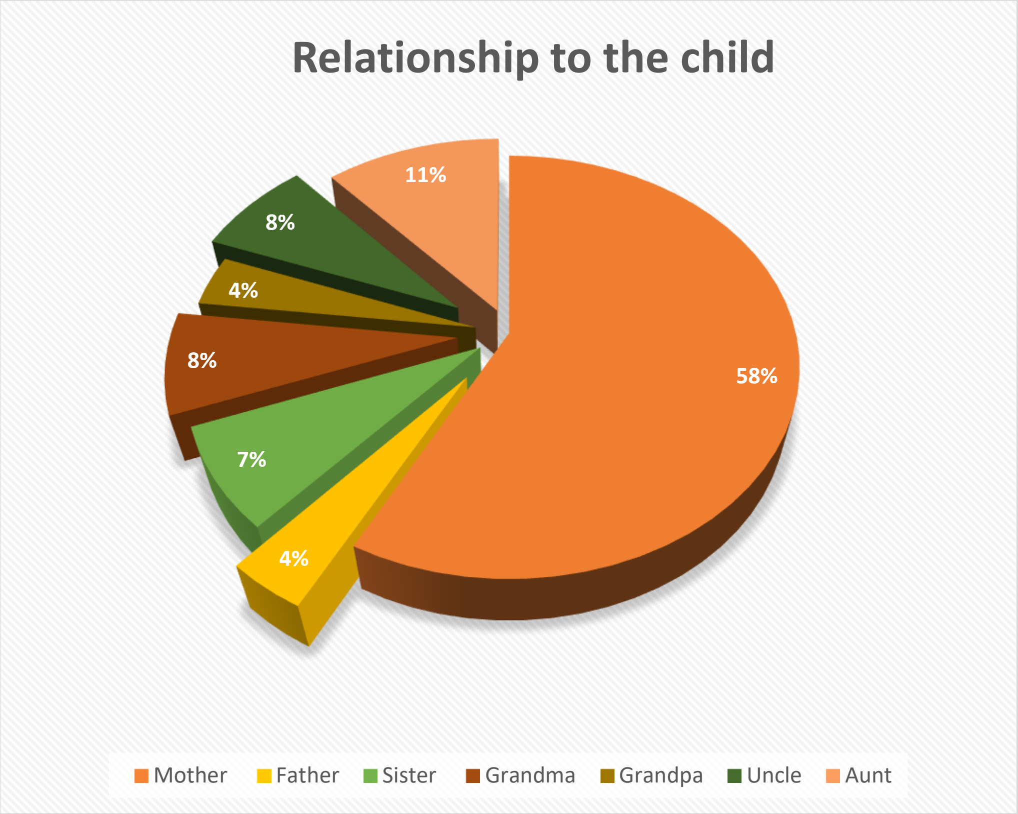

Figure 5.3: Relationship of participants to the child (N=26)

Most fathers were working in other provinces away from home, thus, contributing to the phenomenon of absent fathers. The aunts of the children were close maternal relatives, including the mother's sister. The findings have also shown that the maternal families were playing an active role to support the family with care of children with ID, compared to the paternal families. All aunties and uncles were from the maternal side of the relationships. However, all children were staying with their biological parents, because most families were against institutionalisation of children with ID. Such a practice (institutionalisation) would have been viewed as taboo and an affront to the connectedness of traditional African families, especially in rural settings.

5.2.6 Participants' Educational Qualifications

Figure 5.4 below displays the educational qualifications of the 26 participants. The educational background of the participants is relevant when viewed as an enabling knowledge on whose account participants' exposure and familiarity with the condition of children with ID and its management could be determined or established. The results show that most participants (50%, n=13) had Grade 11 to 12 high school education, while

19% (n=5) had Grade 8 to 10, and Grade 4 to 7 (15%, n=4), diploma at 12% (n=3) and a university degree 4% (n=1).

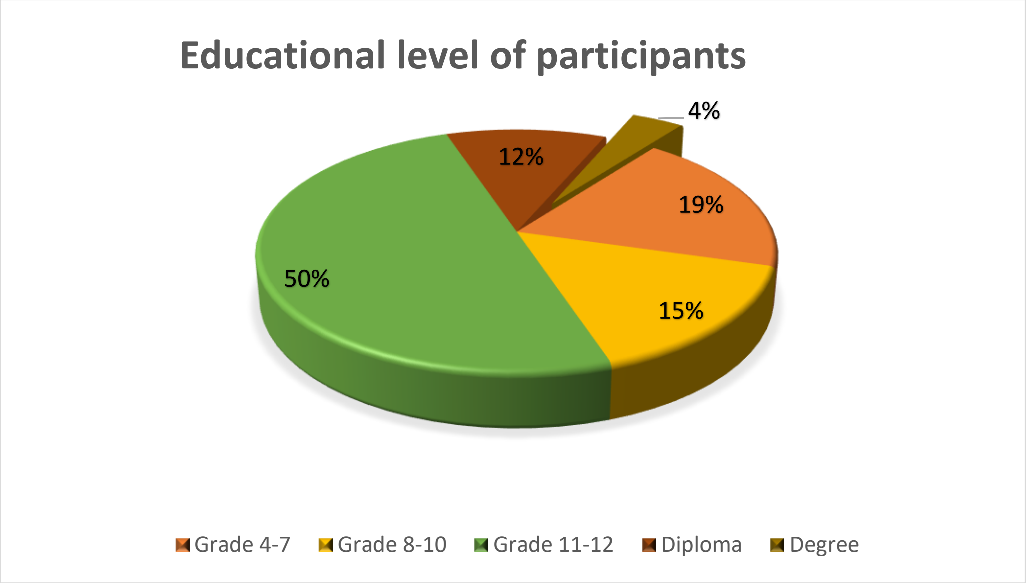

Figure 5.4: Educational level of participants (N=26)

Educational level also plays a major role insofar as understanding the behaviour of children with ID, as well as management and maintenance of their own health status. Most of these participants were able to explain the causes and effects of the ID diagnosis on the physical development of their children. Most participants left school at Grade 12, which is provided freely at basic education level in South African public schools. Most of them indicated that they could not proceed to tertiary education owing to lack of funds.

5.2.7 Participants' Employment Information

Figure 5.5 below depicts employment information of the families. The employment details of participants were included in order to determine the income status of the families. The information in this figure only represents participants who were interviewed, not the families. The finding of this study have shown high unemployment rates of 61% (n=16). Those who were employed were at 23% (n=6), the pensioners on social grant for the elderly were at 12% (n=3), and those who were still at school were at 4% (n=1).

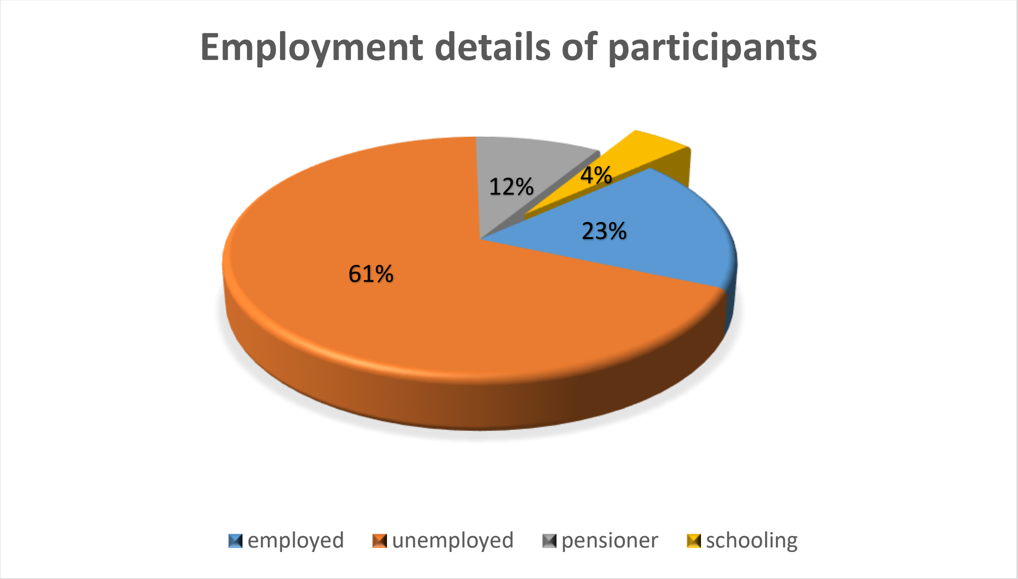

Figure 5.5: Employment status of participants (N=26)

Most of the unemployed participants indicated interest in finding jobs, but were prevented by the responsibility taking care of the intellectually challenged children. However, most families were dependent on the State's disability care and social grant for children as the only source of income to care for family needs. The information findings have shown that most families were living under conditions of unemployment, with the social grants fulfilling a major role to support the families financially.

5.2.8 Participants' Religious Affiliation

The religion of participants played a vital role in providing spiritual support. The families of children with ID are a vulnerable group who believe in any magic or supernatural power that was able to heal their children. All participants (100%, n=26) were Christian by faith and belonged to different churches organisations. However, most of the families were not active church members. Hence, they took most of their time caring for the children and did not to attend church regularly. However, the participants' religious perspectives also play a role in influencing their acquired formal knowledge and accumulated experiences concerning acceptance and management of their children's condition.

5.2.9 The Profiles of Children with ID

Figure 5.6 below depicts the profile of children with ID. Such profiling enabled the study to identify the problems experienced by the children, and the services needed to assist the families in support their children. The findings have also shown that there were more boys (70% (n=19) with ID than the girls at 30% (n=8). These children were raised in single-parent families headed by the mothers, which indicates absent fathers and the potential to influence the boy child’s role modelling and identity quandary. The age grouping of the children has shown that no one was below the age of five years, supporting the findings that most families were not able to identify the symptoms of ID early before these children were diagnosed through the assistance of schools or day care centres.

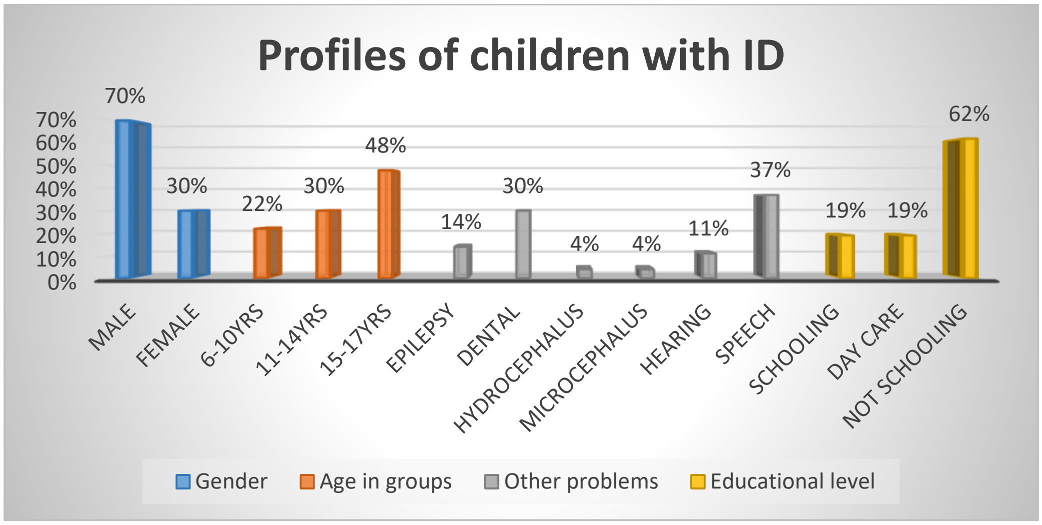

Figure 5.6: The profiles of children with ID (N=27)

The majority of the children (represented by family member or caregiver) were males (n=19, 70%), whereas the females were 8 (30%). Also, all the children (n=27, 100%) received disability grants, with 17 (62%) not schooling; 5 (19%) were schooling while 5 (31%) were in day care. All the children represented above received disability grants, coheres with the high rate of unemployed participants (n=16, 61.5%). Most children were between the ages of 6 and 10 years of age at 22% (n=6), those between 11 and 14 years at 30% (n=8), while those between 15 and 17 years were at 48% (n=13). It is clear that most children were teenagers, indicating vulnerability to behavioural problems and in need of more support from their families. Most children (37%, n=10) were experiencing speech problems, which was evidently an indicator of the need for speech services to support the affected families. Those with dental problems at 30% (n=8) may have exposed the children to nutritional challenges owing to decayed or loose teeth. Some children have lost their teeth, causing them to eat with difficulty and prospects of losing their appetite and malnutrition. Epilepsy was at 14% (n=4), those with hearing problems at 11% (n=3), hydrocephalus at 4% (n=1), and microcephalus at 4% (n=1). This attests to the need for medical care services for effective treatment, which could inevitably incur more costs to the families. The majority of the children (62%, n=17) were not attending schooling, staying home under the care of family members. However, 19% (n=5) were at special schools, and 19% (n=5) were still at affordable day care centres for stimulation. Most children in day care were due for schooling. Their attendance of day care is an indication that the educational needs of the children were lagging behind.

Some families were concerned that their children were not receiving adequate stimulation at day care centres. However, some regarded the day care centres as schools. Day care education differs from that of the special schools, which influenced the participants' belief that the teaching was of a lower standard; therefore, not commensurate with the educational needs of their children. The findings extrapolated from Figure 5.6 further indicate the need for health care services, including dental, speech and hearing, and medical interventions with regular check-ups and follow-ups. The many out-of-school children with ID shows the unequal right to access basic education, which is a fundamental and constitutionally entrenched human right in South Africa.

5.2.10 The Profile of Type of Family of Participants

Figure 5.7 below is a depiction of the participants' household profiles per family type. The participants' type of households showed the different family structures that were living with children with ID. Female-headed households were at 38% (n=11), nuclear families at 31% (n=7), three-generation at 15% (n=4); skip generation at 8% (n=3), polygynous at 4% (n=1), and child-headed households at 4% (n=1) each.

The information above shows that the majority of the participants (family member or caregiver) were in female headed families, followed by the nuclear family. Accruing from this female-headed statistical information, the implication is that women (particularly in low-to-middle-income countries) are further disempowered by the burdened of care in addition to other forms of culturally and/or socio-economically inspired forms of stratification (United Nations, 2008).

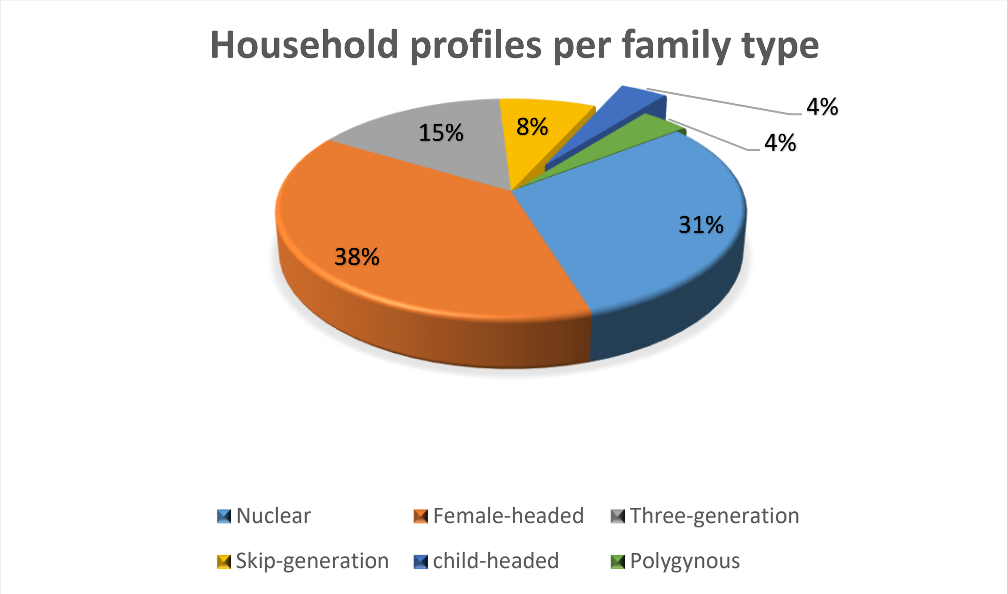

Figure 5.7: Household profiles of participants per family type (N=26)

The figure above shows that most families were female-headed, meaning that even the breadwinner responsibilities were shouldered by the mother of the child with ID alone in an environment characterised by high unemployment and its deleterious challenges on these families. The highest percentage of female-headed households consisted of single parents, divorced, and widowed participants. Some of the households experienced absent fathers who were either away or not paying child support to maintain their children. In such circumstances, the households survived on monthly social grants for the children from the Department of Social Development.

The nuclear families consisting of parents and their children constituted the second highest percentage of family type per household. In most of these families, the breadwinners were men. However, some participants reported present fathers who were not actively involved in the financial sustenance of their families. Unemployment was attributable to some parents failing in their financial obligations to their families.

Most of the communities in the rural areas consist of family households in which uncles and aunts and their children still live with their parents. In such situations, the grandparents were actively involved in assisting the parents to raise their children. The social grants of the parents were utilised as the financial means to fulfil the basic needs of the families. The grandparents were from either the maternal or paternal side of the families.

Some of the grandparents were raising the grandchildren alone in skip-generation families. For survival, these families depended on the care and elderly care grants of the grandparents and the children. Some of families in rural areas had children under the care of the grandparent/s while parents migrated to the urban areas to find jobs. Hence, the burden of caregiving for the child with ID became the responsibility of the grandparents, especially the grandmothers who played a major in attending to their grandchildren’s schooling needs and helping with their homework. Some of these grandchildren had different parents and were cousins to each other.

In one of the families, the mother was not staying with the children because she worked far from home and only came home on weekends. This household was headed by a child who was still in Grade 11, but also had her own child to contend with while taking care of her sibling with mild ID. This sibling was still attending primary school at the age of 16. The self-same Grade 11 child was also taking care of her sister’s child who was working. The polygynous household reported that the father was not always available to support the family members. This polygynous household of two families were living in separate households, with the mother constantly complaining that the husband spent most of the time with the younger wife.

5.3 RESEARCH FINDINGS

This section on research findings premises largely on the thematically generated evidence accrued from the narrated statements of the 26 participants. Accordingly, 7 (seven) themes emerged, namely:

- The need for informational support;
- The need for professional support;
- The need for psycho-emotional support;
- The need for social and community support;
- The need for financial support
- The need for economic infrastructural support; and
- Improved suggestions.

It is worth reiterating that the above themes emerged through the process of qualitative data analysis, cognisant of the research objectives of the study as well. Categories and subcategories developed from the above themes emerged from analysis and interpretation of verbatim transcripts from individual in-depth interviews and focus group discussions. Moreover, the support needs of families living with children with ID emerged as the central theme. The researcher elaborated on all the categories based on literature relating to previous studies. The themes and sub-categories are discussed further in more details in Chapter 6 of this study. Table 5.1 below indicates the main themes, categories and sub-categories.

Table 5.2: Display of themes, categories and sub-categories

Themes	**Categories**	**Sub-categories**
1. The need for informational support	1.1. The understanding of the child with ID	1.1.1 Views on the causes of ID 1.1.2 Development of the child 1.1.3. Limitations of the child
	1.2. Information on management of behaviour of the children with ID	1.2.1. Behaviour challenges 1.2.2. Social interaction 1.2.3. Discipline of the child with ID
	1.3. Information on care of the children with ID	1.3.1. Overprotectiveness of the child 1.3.2. Safety of the child 1.3.3. Caretaking attachment 1.3.4. Medical care of the child
	1.4. Information on stimulation of the child	1.4.1. Self-care development 1.4.2. Language development 1.4.3. Cognitive development
	1.5. Information on legal rights	1.5.1 Rights of children with ID 1.5.2. Rights of families of children with ID
	1.6. Information on the support services available	1.6.1. Services available for the child 1.6.2. Services available for the families
2. The need for professional support	2.1. Collaboration between families and professionals	2.1.1. Communication between families and professionals 2.1.2. Frequency of contact with professionals
	2.2. Referral to relevant services	2.2.1. Mental health services 2.2.2. Speech and hearing services 2.2.3. Psychological services 2.2.4. Community primary health care services 2.2.5. Local government services 2.2.6. Social work services

	2.3. Counselling services	2.3.1. Genetic couple counselling 2.3.2. Sibling adjustment 2.3.3. Co-parenting 2.3.4. Marital conflicts
	2.4. Family-centred interventions	2.4.1. Parenting skills 2.4.2. Problem solving skills 2.4.3. Family empowerment 2.4.4. Adaptability to change 2.4.5. Education of the child 2.4.6. Parental efficacy
	2.5. Home visits	2.5.1. Family therapy 2.5.2. Family coaching 2.5.3. Coping strategies
3. The need for psycho-emotional support	3.1. Family self-care management	3.1.1. Stress management 3.1.2. Hopes for the future 3.1.3. Fears and uncertainty about the future of the child
4. The need for social and community support	4.1. Nuclear family	4.1.1. Family cohesion 4.1.2. Family dysfunctionality 4.1.3. The absent fathers 4.1.4. The roles of family members 4.1.5. Distance parenting
	4.2. Extended family	4.2.1. Support from the in-laws 4.2.2. Support from friends and relatives 4.2.3. Support from grandparents 4.2.4. Father figure support
	4.3. Community structural support	4.3.1. Support from neighbours 4.3.2. Local community organizations 4.3.3. Spiritual organisations 4.3.4. Availability of ID educational facilities 4.3.5. Community awareness of ID
	4.4. The need for support resources	4.4.1. Social networking

		4.4.2. Community based support groups
	4.5. Family quality of life	4.5.1. Role disempowerment 4.5.2. Social life and leisure time deprivation
5. The need for financial support	5.1. Financial impact for the family	5.1.1. Costs associated to the child with ID 5.1.2. Unemployment related to care of the child with ID 5.1.3. Disability grant for the child with ID
6. The need for economic infrastructural support	6.1. Basic needs	6.1.1. Sanitation 6.1.2. Housing 6.1.3. Transport resources 6.1.4. Nutritional needs
7. Improvement suggestions	7.1. Training of families	7.1.1. The emotional wellbeing of the child
	7.2. Provision of material resources	7.2.1. Resources to stimulate the child 7.2.2. Caregiving grant

5.3.1 The Need for Informational Support

The families reported that the information they received regarding ID was inadequate. To that effect, the study found that families lack basic knowledge regarding understanding of the child with ID; management of the behaviour of the child with ID; information on the care of the child; and information on the legal rights of living with an intellectually challenged child.

5.3.1.1 Understanding the child with ID

Understanding of the notion of ID enables the families to meet the demands of the children with ID. To this effect, the study found that the participants' understanding was characterised by three principal factors, namely: views concerning the causes of ID; development of the child with ID; and limitations of the child. These three factors are congruent with the observation by the American Psychiatric Association (2013:31), which showed that ID was characterised by deficits in general mental abilities that result in impairment of adaptive functioning to meet independence and social responsibilities. In addition, acquisition and assimilation of different types of information play a major role in directing the care of their children with ID (Douglas et al., 2017:2774). In essence, truthful information provided to families on planning and managing the care of their child is considered as a way of simplifying processes of the professionals (James, 2012:17). The three principal factors (sub-categories) are discussed below insofar as they reflect the participants' understanding of the child with ID.

5.3.1.1.1 Views on the causes of ID

Families raised different views on what contributed to the diagnosis of their children with ID. The findings indicate that families had difficulty understanding the early signs of intellectual disability, until the children were diagnosed at either the health facilities or school. The following statements reflect such lack of early observation:

> "*My child started to be sick after he fell on his head when he was five months old while carried by his sibling. We took him to hospital and during discharge they told us that he is having problems with his eyes and later was diagnosed with mental retardation*".
>
> "*I was not sure but I realised it when the child was not able to walk. One day she took my sleeping tablets and was sleepy and taken to the hospital. When she woke up after three days, they were surprised by her behaviour and later they told me that they diagnosed her with autism and intellectual disability*".

> "*My child's problems were discovered at birth in the hospital. The skin was very dry after discharge we went home and for follow up back to the hospital for consultation. I was 45 years when I delivered my baby and they told me that it is the cause of the mental retardation*"*.*

> "*My child started while he was on sitting stage. He used to cry throughout. I took him to hospital and they informed me that his bones are not strong. They gave him toys and tried to support him to sit but all failed*"*.*

> *"We recognised ours while he was at the crèche. We took him to hospital and they told us that he is not well*"*.*

5.3.1.1.2 Development of the child with ID

The study findings have shown the families' poor knowledge on development of the child with ID. Most families were not able to identify the abnormal developments of children with ID. Instead, they compared the children with ID to their peers who exhibited typical normal development, as indicated in the following statements:

> "*The child was very young to be observed to indicate whether development was slow. He was small and could not walk properly*"*.*

> "*The child's development was up and down. I tried to train the child the way they showed me in the hospital. The child's development was not well. Everything slowed down. He was able to walk after a long time, maybe after two if I still remember but it took time*"*.*

> "*He was very active and forward than the children of her age. But now everything just dropped beyond normal*"*.*

5.3.1.1.3 Limitations of the child

The results have shown that the families expected the achievements of the children to be above their ordinary capabilities and abilities. They associated the children's difficulties with motor development and self-care skills, feeding, grooming, toilet habits, and communication skills, as indicated below:

> "*I have a challenge with communication because he is not able to talk. I sometimes depend on his guidance, like if he chooses what he wants*"*.*

> "*The child forgets basic things like wiping himself after using the toilet. Sometimes he feels embarrassed and get angry with us or sometimes even crying. We must follow him when he visits the toilet*".

> "*The child does not communicate; she cannot initiate communication. She needs to reminder to bath herself, we taught her. It need patience and some family members get bored and shout at her*"*.*

5.3.1.2 Information on management of behaviour of the children with ID

Families reported unfulfilled support needs concerning information about the management of the behavioural challenges of their children with ID. The study found that behavioural challenges, social interaction and discipline of the child constituted three principal factors related to participants' lack of information concerning the management of children with ID.

The above findings support the view that children with developmental delays (DD) were not excluded from the high risk of exhibiting significant behaviour problems. The range of such problems includes: self-stimulation, and destructive and stereotyping behaviour (e.g. self-injury, aggression, withdrawal, destruction, tantrums, detachment, biting or slapping, consuming inedible objects, disobedience, persistent screaming, and regurgitation of food) (Kaur, 2013:1464; Paliwal & Paliwal, 2014:1440). Notwithstanding the prevalence of these problems, parental lack of knowledge in this regard is inexcusable considering that the National Health Act (No. 61 of 2003) emphasises the right of the user of the health service to have full knowledge of the risks, costs and consequences associated with the conditions or diseases (South Africa, 2004:20). However, the study also considers that legal rights and consumer education are spheres of life not easily understood even under ordinary circumstances by average citizens.

5.3.1.2.1 Behavioural challenges

The results have shown that families were not able to understand and manage the challenging behaviour of their children. They reported strange behaviour, including aggression, destructive and stubbornness, wandering aimlessly and overeating. The main concern was aggressive behaviour that was sometimes inappropriate and became worse when the children could not get what they wanted, as expressed below:

> "*My sibling beats people a lot; he is very aggressive. He doesn't want to be looked at without a reason*".

> "*The behaviour of the child is sometimes aggressive; he is so aggressive and when he is like that his sister hide from him. It is difficult to handle him if one does not know him*".

> "*The child destroys properties like curtains and it was difficult to leave her alone. We always make sure that she does not play next to the windows. I do not understand what she sees in them*".

5.3.1.2.2 Social interaction of the child

Participants expressed that the children with ID found it difficult to socialise with some of the members of the family and community. The families were not able to understand the reasons for the children's refusal to play with other children or to visit other extended family members. This was expressed as follows:

> "*My child doesn't want to go anywhere. He stays at home. He does not want to visit anywhere, even his sister. I even left him alone at home now*".
>
> "*My child doesn't want to meet people outside the family members. He is more comfortable to stay home*".

5.3.1.2.3 Discipline of the child with ID

Families reported that the children showed different mood disorders, which family members found it difficult to manage. In some families, misunderstanding of the children created strained relationships with siblings. The following statements explain the families' frustrations:

> "*He always insults his father for no apparent reason. I try to talk to him but he will always repeat*".
>
> "*My child is having a problem of refusing to be sent to the shop near home to buy bread and he will tell you to send his younger sibling. We cannot force him*".
>
> "*He sometimes show abnormal behaviour; he cries even if not spoken well to by any of the family members*".
>
> "*My child only beats others when he is angry. Most of the time he is quite*".

5.3.1.3 Information on care of the children with ID

The findings revealed that families lack adequate information concerning the provision of adequate care to the child with ID. In this regard, over-protection of the child; safety of the child; caretaking attachment; and medical care of the child emerged as the key sub-categories relating to information on the care of children with ID. The National Health Act (No. 61 of 2003) places the onus on the user of the health care service to have full knowledge regarding the treatment options available to them (DoH, 2004:20).

Information support provides better understanding and assessment of critical situations to the family, and assists the family with problem-solving skills and feedback about the effectiveness of different preventive measures to control and maintain the situation (Guzowski, 2017:27). However, in countries such as the Democratic Republic of Congo, the National Association of Parents of Children with Intellectual Disability (ANAPEHMCO) provides information to families through conferences by inviting speakers to share thematic issues on care and protection of children with ID (Aldersey et al., 2016:26).

5.3.1.3.1 Over-protection of the child

The study results have shown that some families displayed an overly protective approach towards their intellectually challenged children. Some of these families were not willing to teach the children good behaviour, which would eventually benefit both the children and the family members. The following excerpts attest to such over-protectiveness:

> "*I have other children other than him. I think I don't have time for other children, I think that I give more attention to him only, I need training so that I know how to treat other children because this cause conflict*".
>
> "*I must pay attention and listen to the child more than anyone in the family because he is not able to take care of himself*".
>
> *"The problem is that they are very choosy with food and that is very frustrating. They always want to get what they like".*

5.3.1.3.2 Safety of the child

Most families expressed their concerns with the safety of their children with ID. They reported lack of trust in the people and the environment around their children. They expressed their concerns thus:

> *"I feel like my child is not safe. When I went to visit him at school, I found that he has lost two teeth and his lips were blue. After the school transport dropped him, I realised the child was not free until I discovered that it was due to school ill treatment at school*".
>
> "*I wish that boys and girls be separated at special schools for the girls to be protected and safe. Nevertheless, I do not trust them because they do not know when they are doing wrong things. Separation will help and the schools will be safe*".
>
> "*My child sometimes walks around and that is why I worry about his protection. Especially because he cannot fight back when beaten by other children*".
>
> "*If we leave him alone, we must lock the gates so that he does not get access to roam around in the streets*".

5.3.1.3.3 Caretaking attachment

The results have shown that the children with ID were closely attached to family members who took care of them. Some family members, including parents, found it difficult to share the caring responsibilities of the children with other family members. Mothers felt satisfied when they cared for their children with ID on their own, as shown below:

> *"It is difficult to manage the child because he refuses to sleep with his siblings. He sleeps with me and it is not easy because I am married".*
>
> *"I do not believe in taking the child to institutions like boarding. I think that the child will think that I don't like him and have abandoned him".*
>
> *"I am forced to be always available to protect the child and make sure that he plays in the yard because if he goes out there is a problem".*

5.3.1.3.4 Medical care of the child

The findings have shown that most of the children with ID experienced high medical risks, such as seizures. Some of the children were not receiving treatment for such medical conditions and their related problems. Also, some families did not find it necessary to seek medical help to prevent further damage to the brain in children with epilepsy. The following statements attest:

> "*The challenges are when she is fitting, I have to wake up during the night. The child is on treatment but continues to have fits*"*.*
>
> *"The child is sometimes attacked by seizures and I have to attend to him during the night. I always know when he is having seizures attacks and I wake up to attend to him".*
>
> *"I wake up during the night when he is fitting. I can hear him struggling when I am asleep. I must make sure that everything is right with him. The child is not on treatment."*

5.3.1.4 Information on stimulation of the child

The findings have shown that most families lack knowledge on how to stimulate the children effectively. These families were unable to identify and understand behaviour displayed by the children for the stimulation of their senses. The senses include touch, visual, hearing, smell and taste. Hence, most of them regarded daily routine activities of the children as typical development necessary for effective stimulation. Self-care development, language development and cognitive development emerged as the three key sub-categories of stimulation information for the child with ID.

The White Paper for the Rights of Persons with Disabilities (WPRPD) indicates that stimulation programmes for children with ID enables development of learning skills that allow them to be part of their communities (DoSD, 2016:99). However, families are entrusted with great responsibility, since they are considered as the main primary teachers to the development of each child (Uys & Middleton, 2014:551). Home stimulation of all senses and self-care teachings enhance learning development of the child with ID.

Congruent with these study findings (i.e. self-care, language and cognitive development), early childhood development strategies propose that stimulating children in a home environment plays a vital role in nurturing growth, development and learning abilities of children with ID (WHO, 2012:29). Therefore, lack of stimulation (which leads to boredom) increases behavioural problems in children with ID (Gauthier-Boudreault, Gallagher & Couture, 2017:23). The study by Dandashi, Karkar, Saad, Barhoumi, Al-Jaam and Saddik (2015:2) proposed that use of assistive technology systems with computer-based software can stimulate the child to be able to learn and play; while also developing communication ability.

5.3.1.4.1 Self-care development

The study found that most families lacked knowledge on teaching of the children with ID how to perform basic self-care activities. The caregivers reported that they performed most of the children's self-care responsibilities. The families did not possess basic teaching skills to teach the children how to help themselves, as proved by the statements below:

"*He cannot dress himself but he is able to eat or feed himself. He goes to the bathroom and does not know how to pull his trouser up*"*.*

"*We need to feed him up and that takes more time especially if he feed himself. He messes all over if he does it by himself. It becomes a problem when we are in a hurry*"*.*

"*We do cooking, washing for him, dressing and only knows and can identify his clothes*"*.*

"*When she is seeing her period, she can't bath herself and she will just tell me that she sees blood. I will instruct her to bath herself. It is frustrating if she is with the other children*"*.*

5.3.1.4.2 Language development

The families reported that the children have difficulty in expressing themselves for their daily needs. The children were reported to be crying and displayed anger when family members did not understand them. Most family members resorted to television as a stimulant to keep the children busy as well. The following statements attest:

> "*One family member advised us to keep the TV on continuously to stimulate the child. She even cries if we switch it off. She said the TV helps her to be able to talk. She enjoys watching it*".
>
> "I *sometimes fail to understand what he wants, especially around people. I get frustrated because I do not understand sign language. It is difficult to understand him. He is not taught how to talk*".

5.3.1.4.3 Cognitive development

Most families complained that their children experienced difficulties in reading and writing, compared to their normally developed peers. The families also reported slow progress of the children, to which no further assistive interventions were taken by the self-same families:

> "*My child has his own time for playing with other children and most of the time he likes being alone. Even if we force him to play, he just resists. He chooses what he wants to do*".
>
> "*I always stimulate the child and play with her. Even though he does not concentrate. It is sometimes difficult because she get bored easily and does not want to continue to play*"

5.3.1.5 Information on legal rights

Information on the rights of the children with ID and the rights of the families was the sub-categories that emerged from information on the legal rights category. From the study findings, family members were not aware of their legal rights and those of children with ID. Some confused the legal rights to parental roles, even after thorough explanation by the researcher. This shows they lacked information concerning both the rights of the children with ID and theirs as families living with these children.

According to the Integrated National Strategy on Support Services for Children with Disabilities (INSSSCD), one of the support strategies is to involve parents and caregivers of these children in all decisions affecting the children (DoSD, 2009:26). The WPRPD emphasises that children with ID and their families are human beings who are inherently rights-holders. Accordingly, they should enjoy universal human rights, which entail social security, family life, active involvement in cultural and recreation life, access to housing, food security, water, health care services, and education (DoSD, 2016:25).

5.3.1.5.1 Rights of children with ID

The findings indicate that families were not adequately informed about the rights of their children with ID. However, some knew about these rights, but found it difficult to relate them to their situation in a practical manner. This difficulty was shown as follows:

> "*The right to be disabled and leave free and he cannot change himself that is the way he was born*"*.*
>
> "*I make sure that the child is protected from being shocked by the electricity*".
>
> "*The child must listen to me and I have the right to be used to him, to know what he wants and does not like, to listen to him and give him a chance*"*.*

5.3.1.5.2 Rights of the families of the children with ID

The study findings showed that families living with children with ID had inadequate information about their own rights in the context of their child caring, which required special care responsibilities. The following statements attest:

> "*I have the right to live with my child, not to take him to an institution with no reason. I have a right to take care of my child. I have the right not for people to tell me that I must take my child to institution*".
>
> "*I think I have a right to stay in a proper house like RDP. I must have food because I cannot work because I have to take care of the child*"*.*
>
> *"We have the right to provide full care for my child. I fight for her right and protect them*".
>
> "*I compare prices for the food. I bathe the baby, but he can feed himself. Paying school fees, collecting child from boarding school*"*.*

5.3.1.6 Information on the support services available

The lack of information on the services available to the children with ID and the services available to the families emerged as a key sub-category of the need for informational support. Most participants showed poor knowledge on multi-disciplinary team (MDT) or health care support services available to assist with rehabilitation and development of children with ID and their families. This finding correlates with the findings of the study by Shurr and Hollingshead (2017:66), which revealed that the families of children with ID struggled to be engaged in schools and other professionals providing support services to their children.

According to Gilson et al. (2017:348), the likelihood of families to pursue access to support services depend mostly on their awareness of the availability of the resources in the community. Vilaseca et al. (2015:40) identified information needs of families of children with ID including, specific information on disabilities and relevant places for these services for the child and family. The WPRPD stressed on the importance of ensuring access of information about available services to the families of children with ID in order to maintain their dignity and respect (DoSD, 2016:100).

5.3.1.6.1 Services available for the child with ID

The results have shown that most families were not familiar with the services offered for the children with ID. Some were of the impression that the services were only available in the hospitals, as demonstrated in the following statements:

> "*I realised my child at seven years when he was sick and taken to the hospital. He had problems with his eyes. He developed fits and was not able to talk, and was later diagnosed with mental retardation. The child is 13 years old*".
>
> "*Even today the child is not able to see well. He is 14 years old and never attended school at the moment*".
>
> "*I took him to church and he later shuffled on the floor, could not walk and not able to sit. I think mental problem get different treatment from other diseases. I don't know their services*".

5.3.1.6.2 Services available for the families

The findings of the study have shown the need of the family to have access to information on the services that are available to support them and enhance their ability to cope with the challenges of living with the children with ID. The following narrated statements attest:

> "*They think that I don't love my child with ID. I was not coping and needed counselling for this matter. But did not know where to go for help*".
>
> "*I am not sure of the services provided to such families, what I know is that we do not have services for the children*"

5.3.2 The Need for Professional Support

Following the key theme of the need for informational support, the need for professional support also emerged as one of the seven global themes of the study. Most participants raised different challenges regarding the support provided by the professionals. Collaboration between the families and professionals, communication between the families and professionals, and the frequency of contact with professional were the main categories in this regard.

5.3.2.1 Collaboration Between Families and Professionals

The findings showed poor collaboration between families living with children with ID and the professionals providing services to the children with ID. The families raised concerns that the health care providers and teachers were not able to provide support them regarding the care of the children with ID. Balcells-Balcells, Giné, Guàrdia-Olmos, Summers and Masa (2018:51) posit that the family-professional partnership is the mediator for quality of life for the families living with intellectually challenged children.

Families reported that the teachers, social workers, child carers at the crèches, and the community nurses do not provide them with progress reports regarding the development of their children. This created a barrier to communication and negative attitudes towards the support services. Therefore, collaboration of the families with the MDT and agencies enhances the achievement of positive outcomes of the family (Keltner & Steele, 2019:112). However, both the professionals and the families must participate actively in the planning, delivery and evaluation of the care of the children with ID. Moreover, the professionals must be sincerely interested in working and respecting the families, especially parents as equal partners towards growth of the children with ID (Jansen et al., 2017:65).

The WHO (2011:65) report on disability emphasises the importance of dedication to collaboration by the health care professionals to improve the care of the children and their families. Dalmau et al. (2017:643) also support the cooperation between families and professionals based on mutual interactions aimed at identifying the needs of the children with ID and their families.

It is noteworthy that constructive collaboration would also entail mutual respect and communication, enabling parents to acquire knowledge and skills on care of their children with ID (Robert, Leblanc & Boyer, 2014:175). However, Al-Kandari (2014:139) argues that professionals are unaware of prioritisation of the family needs, and do not know everything about the needs of families raising the children with ID. A study conducted in Turkey shows that instructors and counsellors are common professionals working with families raising the children with ID (Cenk, Muslu & Sarlak, 2016:708).. However, the nurses in that country were able to assess the needs to provide care to ensure families' psychological health.

5.3.2.1.1 Communication between families and professionals

The families reported negative experiences related to internal communication with professionals. Families blamed the professionals, especially their children's teachers, for not informing them about the progress of their children, to which the following statements bear testimony:

> "*I was told by one of the learners that my child was sexually abused by another learner. The teachers did not tell me anything, and that worried me, and I decided to take my child out of the school and report the matter to the police. When I made follow-up, the case was dropped without explanation*"*.*
>
> "*Last time I took him to a certain school, I found he was scratched on the face and when asked, I was told that they are not with them over the weekend. I once again found his leg swollen and they told me that maybe a bug or some insect bitten him. I was angry because they did not inform me, and I took my child to the clinic*"*.*
>
> "*When I went to the school to visit my son, I found that he has lost two teeth and the lips were swollen and blue in colour. I was not informed before*"*.*
>
> "*My child lost teeth while at the day care Centre and I was not informed what happened. My family agreed that the child must stay at home*"*.*
>
> *"Most of the time when I am concerned about the injuries of my child at school they just tell me that they are children and they play dangerous games. This worries me because they should take care of them".*

5.3.2.1.2 Frequency of contact with professionals

The findings showed poor contact between the families and professionals who provided services to the families. There was a dire need for families to have contact sessions with local professionals such as nurses, social workers and teachers, which was expressed thus:

> "*We do not know them and do not have contact with them. There was a fine moment when we used to consult the hospital therapist, including speech and occupational but nowadays we do not attend, while they are at school age*"*.*
>
> "*Professionals should come and check on my brother, provide him with the treatment*"*.*
>
> "*The doctor just told me that he won't be able to talk and I just saw the social worker in 2012 when we had family issues*"*.*

> "*The social workers have never visited my child. I even asked them to visit my house but they never came*".

5.3.2.2 Referral to relevant services

Referral is the process of transferring service provision responsibilities to another institution or person (Uys & Middleton, 2014:78). Such referral ensures continuity of care and better mental health for the entire family, especially when personalised and individualised approach employed by practitioners with knowledge of resources available to meet the families' needs (Keltner & Steele, 2019:112). Hence, strengthening of multi-disciplinary teams will enhance effectiveness of the referral chain and improve communication between professionals (Modula & Ramukumba, 2018:12).

Professionals working with families with children with ID have a responsibility of monitoring stress and psychosocial problems and refer them promptly to the relevant support services (Kleefman, Reijneveld & Jansen, 2015:55). However, the WHO's (2011:76) world disability report shows that health care workers often found to be lacking sufficient skills on conditions related to ID. Such lack impedes proper diagnosis and referral to relevant services for further intervention (WHO, 2011:76).

The study findings have shown poor involvement of families regarding the services of the MDT to rehabilitate their children with ID. The families reported inactive participation of services for mental health, speech and hearing, psychological, dental, community health care, local government and social work services.

5.3.2.2.1 Mental health services

The findings of the study have shown the need for mental services for the participants, who stated that the condition of the children with ID and its attendant unmanageable behaviours was often stressful. They intimated their frustrations thus:

> "*The child cannot stay in one place. I once attended support group in the hospital discussing our challenges. The condition of the child is still the same, active before and after admission. She is able to climb trees and high objects more than boys*".
>
> "*The child cannot stay stable. She enters every house door*".

5.3.2.2.2 Speech and hearing services

Some families reported the need for speech and hearing services for the children who were not able to hear properly and had difficulties to express their needs. They stated:

> “*They reported that he is not talking and not indicating when he wants to visit the bathroom”.*
>
> *“For speech and hearing, we only go to the hospital, but we have to make appointment”.*
>
> *“He was not able to talk, not hearing well but was beating other people. We could not observe anything as the child was very young”.*

5.3.2.2.3 Psychological services

Most participants indicated more psychological problems related to the care of the children with ID. Some raised signs of mental disorders, including anxiety and stress related to raising the child with ID, which needed psychological interventions. They averred:

> “*I was frustrated and wanted to ingest poison and kill both my children. I felt the pain*”*.*
>
> “*I feel emotional pain that he is like the way he is, not the same as other children*”*.*

5.3.2.2.4 Community primary health care services

Some raised concerns about the availability of community health care workers who provided support to others families with other chronic conditions, but excluded their families and intellectually challenged children. The families were not actively utilising the health care communities around them for support. They mentioned:

> “*With the clinic visits, I have to queue like all patients and it is difficult to manage the child because he is always running outside*”.
>
> “*Community health care workers only come when they deliver the napkins*”.
>
> “*They do not visit us. We do not know them. I just see others visiting those with other conditions including, Human Immunodeficiency Virus and Tuberculosis”.*

5.3.2.2.5 Local government services

Some families experienced challenges with the services of the local municipalities regarding sanitation and housing. Some reported that they long applied for housing and sanitation from the local municipality, but no visible progress was recorded. Some even struggled to identify the very services that municipalities, as indicated below:

> “*I wish for support and assistance to help my family with donations so that even when I die I do not leave my child in darkness*”*.*
>
> “*We do not have a proper house to stay. I applied for RDP house since 2006 but no response*”.

5.3.2.2.6 Social work services

The families were not utilising the social work services effectively when in need of support. Some even thought that such services were only accessible in hospitals only, as indicated by the statements below:

> "*The social workers told me the things that I did wrong regarding the care of the child and accused me that I do not take care of my child. I am worried because social worker just judged me without getting part of my story*".
>
> "*We once made decision to apply for him to be institutionalised but did not succeed*"*.*

5.3.2.3 Counselling services

Following the ID diagnosis of the child, some participants reported family problems as attributable to this condition. The purported problems included: experiencing couple or marital instability; lack of support from siblings, partners and spouses; and family conflicts. Some family members, especially mothers, expressed their feelings hoping that the researcher would provide counselling sessions to their problems. Genetic couple counselling, sibling adjustment, co-parenting, marital quality and adjustment emerged as the core sub-categories relating to the need for counselling services. Counselling service relates to the process of assisting a person to analyse and improve inter-personal and intra-personal relationships (Uys & Middleton, 2014:261).

As some of the important domains in psychological interventions, counselling programmes improve family adaptations, parental adjustment and competencies in families living with children with ID (Douglas et al., 2017:2742; King et al., 2017:338). Additionally, the Patient's Rights' Charter in South Africa entitles every citizen the right to access health care services without any discrimination. These services include counselling. In addition, counselling of families decreases their stress levels, increases self-esteem and reduces the risk of disorders related to anxiety (Mulligan et al., 2014:162). Moreover, congruent with these study findings, Sajjad (2011:76) found that counselling is very crucial for enabling family members' creation of a friendly and positive home environment for the children with ID.

5.3.2.3.1 Genetic couple counselling

The study findings have shown the need for genetic couple counselling for some families who reported that the fathers were not actively involved in the care of their children with

ID. As indicated below, some family members reported that their partners blamed them for the condition of the child:

> *"We struggle financially; my husband is not part of the care of the child. My child needs total care so I have to work to support my children as the child is eating a lot".*
>
> "*It is very difficult. I had conflict with my husband as he once told me to take the child to his biological father. He married me with the child*"*.*

5.3.2.3.2 Sibling adjustment

Some families reported that some of the siblings did not accept their brother or sister who suffered from ID. As such, families found it difficult to involve the siblings actively in the care of the child with ID. The siblings did not accept the fact that the child with ID is one of their own. The following assertions confirm the above-cited sentiments:

> "*I am worried about my children not supporting their sibling, they always treat him badly. Other school children also ill treat them*"*.*
>
> "*The children have accepted her but they sometimes feel frustrated when she cannot initiate any communication. They are the ones who will try to talk to her*"*.*
>
> "*The main challenge is in the family, they don't understand his moods and they say wrong words and sometimes beat him up. They don't understand him*"*.*

5.3.2.3.3 Co-parenting

Some mothers reported that fathers were passive in the care of their child with ID. They expressed that their husbands were not playing supportive roles expected from parents. They commented as follows:

> "*I am the only one who is more worried about the care of the child. My husband does not show interest in the child. He fails to meet the demands of the child. At school, they want each child to have a casual day T-shirt and I do not have money to buy it. I feel so burdened*"*.*
>
> "*The father is not supportive at all. I feel burdened by family responsibilities and lack of support*"*.*
>
> "*My husband is only now that he is changing to show a slight care towards the child*"*.*

5.3.2.3.4 Marital conflicts

The findings of the study have shown that families of children experience marital problems. Most parents were divorced after the diagnosis of the child with ID. In many instances, the parents blamed each other for the genetic causes of the condition of the child, as the following statements testify:

> "*It is very difficult. I had conflict with my husband as he once told me to take the child to his biological father but he was quite aware that my child was having disability before we marry*".
>
> "*My husband is having affair with another woman that I am aware of. I also had an affair to relieve stress but he does not know about it. At least my boyfriend supports me more than my husband*".

5.3.2.4 Family-centred interventions

Family centred-interventions emerged as a manifestation of the need for professional support in which parenting skills, problem solving, family empowerment, and adaptability to change, education of the child, socialisation skills, and effective parenting emerged as subcategories. Family intervention focuses mainly on the steps taken by families to enhance their coping abilities and fulfilling the children's needs (Blacher & Gersch, 2014:3; Cenk et al., 2016:708; Crnic et al., 2017:441). Family intervention also provides intensive multi-factorial approaches to improve family functioning and coping skills (Mulligan et al., 2014:163). In addition, family-centred interventions involve and encourage parents' active decision-making capacity in the promotion of quality life for their families (Balcells-Balcells et al., 2018:51).

It is noteworthy that family centred-intervention is inevitable, considering the effects of raising children with ID on the psychological status of their caregivers. This finding supports that of a study by Dalmau et al. (2017:643), which accentuated the importance of collaboration between families and professionals to promote early family-centred intervention model (FCM). The model enables the family to control difficult situations of raising children with ID. Moreover, the FCM should focus on each family's goals and expectations. However, professionals providing services to children with ID propound that the families themselves should be actively involved in intervention planning as the primary caregivers (Robert et al., 2014:174).

5.3.2.4.1 Parenting skills

The study revealed lack of parents' intervention skills to ameliorate the behaviour of the children with ID effectively. Some of the families reported that these children exhibited defiant behaviour when instructed to do something, and some parents resorted to taking them to care facilities for institutionalisation, as shown below:

> "*It is difficult because if you go with him to the shop he will pick all things at the shop*".
>
> "*I went with my husband to the social workers to ask for space in institutions for disability*"*.*
>
> "*My child likes to chew throughout the time and we need to put food available for him*"*.*
>
> "*I don't feel free and well because sometimes it is difficult to manage the children and not easy to handle them*".

5.3.2.4.2 Problem solving skills

The results have shown that some families were not able to support each in solving their own internal problems as a unit. They averred:

> "*It is just that I accepted but as a parent, I feel that I need to accept everything*"*.*
>
> "*One of my husband's family stole my bank card and Identity document and took it to the newspapers indicating that I don't take care of my child*"*.*
>
> "*My husband is not supporting us financially. Even when he was working, he will buy clothes for girls only. My other challenge is that I cannot meet all the child's needs*".

5.3.2.4.3 Family empowerment

The participants reported lack of professional family empowerment programmes to encourage their active participation in the care of their children with ID. The following statements demonstrate their preparedness to be taught how to raise children with ID, notwithstanding some instances of disappointment by the professionals:

> "*I am attending early childhood development training which I pay the fees. It helps me to have knowledge to take care of the child*".
>
> "*I enrolled for psychological support course so that I can acquire relevant information on how to take care of my child*"*.*
>
> "*The social workers called me to their offices and blamed me that I don't take care of my child*".
>
> "*I was not treated well by the professionals regarding care of the child and the grant.*"

5.3.2.4.4 Adaptability to change

Most families showed difficulty in adapting to the demands of caring for the child with ID. However, some families gain personal growth through their religious beliefs, which strengthened their adaptation to changes engendered by with the new circumstances of living with children with ID:

> "*The father said that the child must not be seen by people. He doesn't understand him*".
>
> "*The biological father accepted him but his wife telephonically told me directly to come and fetch the child*".
>
> "*I was disturbed, lost and I was asking myself why my child was like this. I used to hide the child because of the big head*".
>
> "*It is just that I accepted but as a parent I feel that I need to accept everything*".

5.3.2.4.5 Education of the child

The study found that most children are not attending schools or day-care centres owing to the fact some families were not willing to arrange for such attendance. Some reported that they did not feel comfortable to take care of their children personally irrespective of the problems with payments:

> "*My child was attending at one of disability school but I took the child from school because most of the time they will tell you to come and take the child very often*".
>
> "*My child lost teeth while at the school centre. My family agreed that the child must stay at home*".
>
> "*We need to see them learning according to their capabilities, including gardening, soccer, athletic, brick laying to equip themselves*".
>
> *"I think if my child can attend school, she can learn skills to be able to work for herself. I am just praying that things will change".*

5.3.2.4.6 Parental efficacy

Some families reported poor confidence regarding the care of the child with ID. Some reported that they were incapable of meeting the demands of the children with ID, as indicated below:

> "*I can be able to do some of the things but others I'm not sure*".
>
> "*I wake up in the middle of the night not knowing what to do. It is not easy to raise this type of a child*".
>
> "*I even asked the social workers to visit my house but they never came. I was accused several times for poor care of the child but no one follows me up*".

5.3.2.5 Home visits

Providing support to the family starts with home visit sessions, which are integral to evaluating care and progress of the child, including implementation of training and advices provided to the families by professionals (Uys & Middleton, 2014:301). Accordingly, family therapy, family coaching and coping strategies emerged as vital aspects of the home visits category. Uys and Middleton (2014:301) concur that home visits are an assertive form of community outreach approach directed at understanding the physical, social and emotional being of affected families and children. The UNICEF's (2015:94) parenting support policy commends South Africa's home visiting programmes aimed at promoting and assessing family needs, which also strengthens the relationship between families and the professionals.

Home visit programmes were developed to respond to family problems and in instances where access community-based support was not possible (Butcher & Gersch, 2014:1). The early childhood development disability is a manifestation of home visits by community workers to the families of children with ID, aimed at providing centre-based support to increase the confidence and competencies of raising children (WHO, 2012:29). However, the present study found home visits particularly important for family therapy and coaching, as well as coping strategies.

5.3.2.5.1 Family therapy

The findings have shown that the families were not coping with the extent of care required for children with ID. These families experienced problems that needed the interventions of professionals in order to express their feelings through therapy sessions. The following narrative statements bear testimony to their coping challenges:

> "*They think that I don't love my child with ID. I was not coping and needed counselling for this matter*".
>
> "*The social workers called me to their offices and blamed me that I don't take care of my child*".
>
> "*I feel pain that my brother is like this, why he is not the same as other children. I wish the social workers can help us*".

5.3.2.5.2 Family coaching

The participants reported the need for coaching on the care and management of their children with ID. Some even indicated their perceived incompetence to care for the children. They expressed their need for coaching by professionals as follows:

> "*They told me that I will teach him everything that a child need for development. I never received any special training on how to care for the child. It was just verbal advice*".

> “*The main thing is about training about the care of the child because sometimes we do mistakes out of our knowledge*”.
>
> “*They say that I use his grant money to buy myself expensive clothes. The community told the social workers that I drink alcohol with the social grant money*”*.*

5.3.2.5.3 Coping strategies

Some participants experienced challenges of coping with the ID diagnosis and living with the affected children. Some raised that they accepted the situation under duress, as indicated below:

> “*Most of the time we just accept that God gave us and there is nothing we can do*”*.*
>
> “I *am a person who believes in God and I told myself that I must just accept. I accepted that he is my child, there is nothing that I can do, and I can’t run away from him. I think I must accept living with the child*”*.*
>
> “*I am not coping, every time I look at her I am asking myself how she will cope or what will happen if I pass on*”.
>
> “*I just accepted but at the beginning I was not coping. I always take whatever is happening and take it very light*”.
>
> “*As a man I don’t find it as a problem because whether I cope or not the child is here and I can’t I need to show support to my sister to raise her*”*.*

5.3.3 The Need for Psycho-Emotional Support

The need for psycho-emotional support emerged as one of the key themes supporting the needs of families living with intellectually challenged children. In this instance, family self-care management was found to be the only main category, complemented by three other sub-categories, namely: stress management, hope for the future, and, ironically, fears concerning the unknown future of the child with ID.

5.3.3.1 Family self-care management

Some participants experienced the challenge of inadequate time to take care of their personal needs due to the demands exerted by more time needed to provide sufficient care to their children with ID. Stress management, hopes for the future and fears and uncertainties about the future of the child are sub-categories that emerged from this category. Self-care practices of family members play an important role in family interventions to cope with the problems of raising a child with ID (Keltner & Steele, 2019:113). In many instances, families react differently to the birth of a child with ID, depending on the characteristics and coping abilities of the family members.

5.3.3.1.1 Stress management

Most families reported stress resulting from caring responsibilities of the children with ID. Some families stated continuous stress related to the developmental impairment of the child with ID, and were not able to manage the situation. This was stated as follows:

> "*I was stressed for the first weeks after been informed from the hospital that my child is suffering from Intellectual disability. I am depressed by the slow development of the child but there is nothing I can do he is my child*"*.*
>
> "*I am just stressed because he is now a grown up and I can't put him at my back to take him to church anymore*"*.*

5.3.3.1.2 Hope for the future

The families indicated their main wishes and hope for the child centred largely on the acquisition new skills that would facilitate their independence and future provision. They emphasised the importance of learning centres to facilitate training in career-oriented skills. The following narrated statements are reflective of the hope for the future:

> "*We need to see them learning according to their capabilities including, gardening, soccer, athletic, brick laying to equip themselves*"*.*
>
> "*I wish that the child can learn skills to be able to take care of himself. Safe place for my child, like when I am going out for my children to remain safe. I wish my child can work*".
>
> "*I wish my child can have skills to help himself because he will end up being a burden to everyone. I wish he could work to support himself*"*.*
>
> "*I wish he can learn career skills like gardening to be able to work and take care of himself. I really wish my child can work*"*.*

5.3.3.1.3 Fears and uncertainty about the future of the child

Family members, especially mothers, showed great concern about the future of their children with ID. They displayed and expressed great sadness about the uncertainty of their children with ID's future as they depended largely on their families for survival. Some were even tearful and frustrated, stating:

> "*I am worried about his future*"*.*
>
> "*My fear is that when I have passed on what will happen to the child*"*.*
>
> "*My main fear is that what will happen to the child if I die because she needs more care. Her sisters are staying in their own families*"

5.3.4 The Need for Social and Community Support

The study findings have shown that the families were in need of social support to survive the challenges related with living with intellectually challenged children. The theme of the need for social support was categorised further into the nuclear family, extended family, community structural support, the need for support services and family quality.

5.3.4.1 Nuclear family

The participants raised a concern on the lack of unity in some family members to support each other. Family cohesion, family dysfunction, absent fathers, the roles of family members, and distance parenting emerged as subcategories in this category. The White Paper on Families (WPF) stipulates that the nuclear family consists of parents and biological, adopted, or fostered children (DoSD, 2013:3). Some families were not able to function as a unit with expected roles of each family member (Townsend & Morgan, 2018:208).

In essence, the provision of family support is an important process to enhance the quality of life of families. Family support can also address a range of hurdles in raising a family member with ID. The intimacy of kinship relations in a nuclear family depends on cooperation and maintenance of reciprocated support for each other (Pan & Ye, 2015:362). However, in the present study, most families were living with grandparents, uncles and aunts with their children.

5.3.4.1.1 Family cohesion

Participants reported poor relationship between family members, which result in poor support. Mothers showed more concern about the behaviour of some of the siblings and other family members on the care and support of the children with ID. These mothers mentioned:

> "*The other children do not care much. The 11 years old does not understand or like his brother, when asked to give him food, he just throws the plate. I am not satisfied the way he treats him. I am also worried because he is the one who sleeps with him as he sometimes has [epileptic] fits during the middle of the night*"*.*
>
> "*Other children do not support me. Only one child cares about her sibling. Others think that I always care about him alone*"*.*

5.3.4.1.2 Family dysfunctionality

The study revealed that some of the families became dysfunctional after the birth of the child with ID. Meanwhile, some family members were still struggling to interact with the child with ID. They intimated:

> "*I was disturbed, lost and I was asking myself why my child was like this. I used to hide the child because of the big head. The whole family is still frustrated because she is not able to do some of the things without supervision*"*.*
>
> "*Only one child cares about her sibling and she guides me continuously. The other children do not care about and they separate her from others. If I have to go somewhere I will send her via a taxi to her sister*"*.*

5.3.4.1.3 The Absent fathers

The study findings revealed that most children with ID grow without the presence of their fathers, who were absent either because of work, death, divorce, or separation and breakups with the mothers. The following statements bear testimony:

> "*I have separated with all the fathers of my children. We did not agree on lot of things. No one visits the children. I do not want to be involved with their lives anymore. I have decided to stay alone*".
>
> "*The father of my children comes home only month end and during leave from work. He just sent us money every month to take care of the children's' needs; he loves his children a lot*".
>
> *"My husband is very busy. He is a taxi driver and spent most of the time at work. He wakes up at around 04:00 in the morning and home late sometimes when all children asleep. I am the one who make sure that children do their schoolwork. He is a very responsible man*"*.*
>
> "*I am just staying with my children only after the death of my husband. My family stays very far. I provide everything for my children but just trying*"*.*

5.3.4.1.4 The roles of family members

The study findings show that some family members were not participating actively in the care of the children with ID. Most of the caregiving roles were left to the mothers, who mentioned that:

> "*A four-year child is the one who is the one who always assist me or remind me of things that I forgot regarding the care of his brother*"*.*
>
> "*He is just a baby as I do everything for him and he depend on me*"*.*
>
> "*I wake up early in the morning bathing her and feeding her, so that she remains clean*".

> “*I am bathing him, make sure that he eats and drinks medication. I must make sure that he is clean*”*.*

5.3.4.1.5 Distance parenting

The results have also shown that families were experiencing distance parenting for the children with ID because some of the parents were staying away from home owing to work-related reasons. The following participant responses reflect their views in this regard:

> “*I am the one responsible for everything. Her mother is working in Gauteng and only comes to visit us once in a month”*.
>
> “*My husband works far and comes home month end. He makes sure that we get everything that we need but things are very expensive. He pays university fees. He is about to retire and that will help to take care of our daughter together*”*.*
>
> “*I was the one doing everything because my husband was at work in Gauteng. I made sure that my children grew like other children. I tried because it was not easy and I have to leave work to take care of my son*”*.*

5.3.4.2 Extended family

The White Paper on Families in South Africa defines ‘extended family’ as a multi-generational family that may, or may not share or live in the same household (DoSD, 2013:3). Most extended families in this study were aunts, uncles and grandparents who stay with families together in one household. Families reported lack of support from extended family members. In this regard, the attendant sub-categories were: support from the in-laws; support from friends and relatives; support from grandparents and father figure support elements.

The distance parenting study by Seepamore (2015:573) posits that in African families, child upbringing is the responsibility of all extended family members. Hence, friends and in-laws play important roles as extended families in providing informal support to the families’ social network (Collings, Grace & Llewellyn, 2016:492).

The support of extended families mostly bolsters resilience of families to cope with their challenges (Keltner & Steele, 2019:106). However, Pan and Ye (2015:359) posit that the extended family is mobilised to take care of persons with intellectual disability (PWID). Additionally, the extended families’ traditional responsibilities and obligations to support their families without expecting equal reward remain the first principle.

5.3.4.2.1 Support from the in-laws

The study found that caregiving was rotated among nuclear family members who were living with the child. The in-laws supported few families, while some reported that the paternal families blamed them for the cause of the diagnosis of the child with ID. These views were captured thus:

> "*I actually have anger towards the paternity family of the child. They do not care about the child. His father died 10 years ago. I only forgave them but will never forget what they have done to me*".
>
> "*One of his family member stole my identity document and photo and took them to the newspapers to make stories that I do not take of my child with ID*"*.*
>
> "*I get support from my family, the maternal side only; they live in Gauteng. I visit them once when I have money*"*.*
>
> "*The paternal family visits us sometimes even though they stay not far from us. They will come only when my husband is home. Maybe month end*".

5.3.4.2.2 Support from friends and relatives

The families reported poor support and rejection from relatives and friends who were not actively supporting them. The findings have shown that the families have lost contact with the relatives and friends who play a major role in informal support, which was expected to be easily accessible. To this end, the participants reported thus:

> "*I do not have parents and my two sisters have died. My family never visited us*"*.*
>
> "*Nothing from the family relatives, we do not receive support from them. They do not care*"*.*
>
> "*I used to have friends, but because I am always busy. I have lost contact with them*"*.*
>
> "*I am the breadwinner for my siblings too. I have one brother and two sisters and I don't know where my younger sister is*"*.*

5.3.4.2.3 Support from grandparents

The study results revealed the role played by grandparents in supporting families of the children with ID. Most families reported more of maternal, than paternal, as confirmed in the following statements:

> "*My mother is always support she visits us regularly. My children are used to my parents. The mother of my husband takes time to visit us*"*.*
>
> "*My mother helps me with care of the child. I call her to come and take care of the child when I am for shopping because I cannot leave the child alone*".

5.3.4.2.4 Father figure support

The findings highlighted the role played by uncles as father figures to the children raised by the female-headed households where father were absent. The uncles were relatives from the maternal side of the children. The following statements testify to the father figure effect:

> "*I always try to help my sister to raise the children. I try to be them time and again so that they are not involved in things that are out of line*"*.*
>
> "*It is not easy to raise the children without a man in the house because sometimes they do as they want especially boys. Otherwise, I am used to that and we don't know where my brother is but I know that he is alive*"*.*
>
> "*My brother tries a lot. I always tell him when the children give me problem. As a man, he is able to handle them. The father's brothers visit us after a while but I wish the children can have relationship with them because they are same blood"*.
>
> "*I am hurt to see my daughter raising the children alone. I have raised mine together with their mother. Sometimes boys are difficult to handle and they need strong person to discipline. But it is better because their uncle is assists to guide them*".

5.3.4.3 Community structural support

The WPRPD identified that the following interventions were pertinent for improving community living outcomes for PWID and their families: building socially cohesive communities and neighbourhoods; building and supporting families; accessible human settlements or neighbourhoods; access to community-based services supporting independent living; and protection during situations of risk and disaster (DoSD, 2016:72).

When analysed further, the theme of the need for community structural support generated five essential subcategories, namely: support from neighbours; support from local community organisations; spiritual organisations and availability of ID educational facilities.

Every family can be affected differently by the type of ID of the child, depending on the structure of the community to which they belong and the support they receive (Akturk & Aylaz, 2017:343). Hence, it is anticipated that communities should actively work together to achieve their mutually agreed upon shared goals to improve the living condition for all its members. The findings of this study cohere with John et al.'s (2017:677) postulation that the availability of structural support in the community not only helps to improve the child's functioning, but also becomes an affirm the family's own efficacy.

5.3.4.3.1 Support from neighbours

Contrary to expectations, families of children living with ID reported that their coping support efforts were stymied by the inactive involvement of neighbours, as demonstrated below:

> "*The community that we are living in does not care and also not support us. They do not care about the neighbourhood".*
>
> *"Neighbours do not support us. They always tell their children not to play with my child. They thought I would always keep my child in my house. Neighbours are a challenge when it comes to support*"*.*
>
> "*The neighbours think that I don't take care of my child because when my child goes to their houses they give him food*"*.*

5.3.4.3.2 Local community organisations

The study found a lack of intervention by local community structures to support the affected families. The families complained that there were health care workers in their communities who were able to visit and provide support to others families who live with other chronic conditions. They also reported that they lost contact with the faith organisations for support, as shown below:

> "*The hospital will sometimes admit my child. The home-based care providers never came to visit us. I am staying next to two home based care services but they never care to visit my house*"*.*
>
> "*My child was sent back home by the previous schools without a reason. I am tired of taking my child up and down*"*.*
>
> "*We have 3 care workers in our village but they never care about us. I think that they do not come because my child does not receive treatment*".

5.3.4.3.3 Spiritual organisations

The families reported poor support from spiritual faith organisations. They reported that the churches never make follow-up to find out the causes of their irregular church attendance. The intimated:

> "*I even told the pastor that I will not attend the service as usual. I only attend church when there is someone to stay with her at home. The church congregation never visited us*"*.*
>
> "*I have a problem with attending church because people become tired of my child's behaviour. Especially because the child will just grab things from others*"*.*

5.3.4.3.4 Availability of ID educational facilities

Families reported lack of access to specialised schools for children with ID. Some reported that available schools were far from their villages, and it was difficult for their children to attend as day scholars. Owing to the care dependency of their children, some families were not comfortable keeping their children in those schools. To that effect, they commented as follows:

> "*Can they build free special schools to save us money at least we will continue to pay transport. Free schools or school fees funds to meet us half way because the grant money is not enough at all*".
>
> "*I just ask for the government to provide special schools to train our children because she is unable to talk*".
>
> "*I wish my child can have skills to help himself because he will end up been a burden*".
>
> *"With the school that they were attending, they do not learn anything. They need to teach the child how to write, how to play, to exercise and not just to go and spend the day doing nothing. The school that we have only assist with babysitting not learning any activities*".

5.3.4.3.5 Community awareness of ID

The study findings revealed that neighbours of families living with the children with ID lacked ID information and awareness. The families mentioned further that their neighbours did not understand the behaviour of children with ID, which is exemplified by the following statements:

> "*She enters every house doors and neighbours think that she is a witch because they do not understand her behaviour. People looked surprised by his behaviour."*
>
> "*Some community members do not accept him and others throw stones at him. I do not understand how they view him*".
>
> "*The child roams around and works for community and they pay him less money. He fetches water for them*".
>
> "*They get crossed when he goes to the neighbours and eat their food. They think that I do not take care of him*".

5.3.4.4 The need for support resources

The families reported lack of access to support resources, which inhibited their capacity to cope with the level of care required for children with ID. Social networking and community-based support groups emerged as the foremost two subcategories in the need for support resources category. The families reported that they were only able to access the support services during hospitalisation of their children. This finding corroborates Schmidt et al.'s (2017:99) perspective that accessibility to existing support services was a major problem to parents of children with ID. Such a state of affairs justifies the need to ground essential services to hospitals and primary services close to the communities. Such grounding is further justifiable, considering that rural communities with middle and low incomes were the most vulnerable group lacking support resources (IASSIDD, 2013:424). However, non-governmental organisations were aptly positioned to actively support vulnerable families, although their services were more oriented to urban areas (Pan & Ye, (2015:353).

5.3.4.4.1 Social networking

Participants expressed lack of networking resources to meet other families who shared the same experiences of living with intellectually challenged children. Most families thought they were the only ones experiencing problems relating to the care of children with ID, and decided to isolate themselves from society in order to confront their situations. The following statements attest:

> "*I am used to this life, not on the streets. I'm worried that I will be used to the care because I cannot take an hour without him*".
>
> "*I have accepted but it gives me problems if I have to attend funerals over the weekend. People think that I am not part of them forgetting that I have a stumbling block and it is difficult for me to move*".
>
> "*I joined my friends' club before the birth of child, but I don't attend anymore because when I come back home late my partner fight me thinking I don't support her to care for the child*".

5.3.4.4.2. Community based support groups

The study found the need for support groups to enable affected families' coping with the challenge of caring for their children with ID. As caregivers, the families felt isolated, and regarded membership to a support group as a remedy to enable their contact with people in a similar situation. They believed that the support group would enable and encourage them to express and share their feelings and experiences with other families. In this regard, they averred as follows:

> "*Nothing, no support group. Care centre suggested a support group but parents never attended the meetings. Parents do not seem to be interested. They report that they are always busy*".

> "*I delivered in Gauteng Province. I joined support group. Centurion officers were coming every day in the afternoon to give us information… I miss that group since I came to Limpopo*".

> "*I sometimes visit one of the mothers who have the same child as mine for support and advice*".

> "*I always visit my mother for support and advice. She is old and has experience of life.*"

5.3.4.5. Family quality of life

The families reported poor FQoL based on the demands of caring for the children with ID. Role disempowerment, limitation of social services and leisure activity time emerged as the main subcategories of family quality of life.

As the principal and most permanent support setting, the family plays the most important role in deciding the wellbeing of the child with ID (Sajjad, 2011:76). However, the loneliness experienced by the family as caregivers of the children with ID has a negative impact on family life (Sajjad, 2011:76). Hence, it is very essential to provide the family with adequate support services that will improve their quality of life (Irazabal et al., 2016:8). In addition, Schmidt et al. (2017:88) posit that families need a range of competent professional, emotional and informal support systems to achieve a quality of life that enables them to overcome the challenges of living with intellectually challenged children.

5.3.4.5.1 Role disempowerment

The families reported feeling of disempowerment to perform parenting roles linked to the demands of caring for the children with ID. Some participants felt that caring for the children with ID lowered their self-esteem, which they expressed thus:

> "*I need to find work, I have children. I need to care for my children; I am just sacrificing to look after this child. As I am supporting my sister*".
> "*I have the rights of living better life than where I am now. To tell the truth I am just stuck here. I can go and look for a job as I have qualifications*".

5.3.4.5.2 Social life and leisure time deprivation

The findings showed that most families sacrificed their own wellbeing, social life and leisure time for the benefit of the children with ID. Families devoted a large amount of time and effort to purposeful activities for the care of the children with ID. Some of the participants felt overwhelmed by the care demands of the children with ID. The following statements demonstrate the aspects of self-deprivation and burdensome care demands:

> "*It is difficult to attend community activities because it is difficult to leave the child alone. We end up staying at home*".
>
> "*I cannot attend to the funerals and this worries that what will happen if it is me*".
>
> "*I am stressed by doing one thing every day. I will go out to the neighbour who guides me but I will not even take one hour. I am used to home all the time*".
>
> "*It is like I am in jail. I volunteered to care for the child; I cannot do anything, and nannies do not stay for more than two weeks*".
>
> "*I play music and stay in the house for the whole day. I am used to it. I was grown up by my grandma who was strict on us and taught us that way*".
>
> "*I sometimes want to take the children out but I cannot do it alone because she becomes overexcited and uncontrollable as a man I can't manage. I end up taking them back home before we enjoy*".

5.3.5 The Need for Financial Support

Consistent with their need for financial support, the participants categorically mentioned the financial impact and implications of raising their children with ID on the families. It is noteworthy that the financial impact emerged as the only category in this regard.

5.3.5.1 Financial impact for the family

Most families reported lack of finances to meet the demands of living with, and caring for children with ID. Some were dependent on social grants, and those employed were not able to meet the needs of their families. Three associated subcategories emerged from the financial impacts of raising intellectually challenged children. These subcategories were: associated costs, unemployment and social grant for the child with ID.

Families raising children with ID experience added financial pressures due to unemployment and its concomitant ramifications (DoSD, 2016:111). Additional pressures could be the result of medical costs, assistive devices and special care (Saunders et al., 2015:41). Nonetheless, parents of children with severe and profound disabilities could benefit from poverty alleviation support programmes in their communities (DoSD, 2009:31).

5.3.5.1.1. Costs associated to the child with ID

The families reported extra costs related to the demands of the children with ID. The main extra costs raised were related primarily to the health and education of the children with ID. The cost factor was reported thus:

> "*Whenever I take child to school they need money and I have to pay transport because we don't have special school*".
>
> "*The school fees depend on the type of disability of the child*"*.*
>
> "*We must pay funeral services for the children with ID*"*.*
>
> "*As the head of the family, I try to buy more food for him. The grocery that I buy sometimes finish before the end of the month but I make sure food is available. We buy special food for him.*"

5.3.5.1.2. Unemployment related to care of the child with ID

The results showed that most mothers were unlikely to be engaged in full-time jobs because the demands of caring for children with ID made such full-time engagement virtually impossible. It was very difficult for them to choose between their children and work. In most cases, such difficulty deprived them of the opportunity to generate poverty alleviation income for their families. The latter view was articulated thus:

> "*As parents we are not able to work because we cannot leave them alone. They need someone to look after them full time*"*.*
>
> "*We cannot find jobs far because we need to be there for the children*"*.*
>
> "*The school transport fetches him at 08:30 and brings him home at 16:00. It is difficult for me to find work. The reason is that I have to look after my child. In most cases, no employer can agree on the employee to work less hours. If I am not home, he goes out of the yard*"*.*

5.3.5.1.3 Disability grant for the child with ID

The families reported that the State's grant for children with disability was not enough to cater for the children with ID's needs. Unemployed female-headed families were the most affected. The following statements reflect the participants' frustrations with the grant itself:

> "*The child's grant is not enough for his needs*".
>
> "*I am not working, the grant for the children I pay R200 for transport of the child, school fess R150 per month and pocket money for children, burial society for the whole family and groceries*"*.*

5.3.6 The Need for Economic Infrastructural Support

The need for basic infrastructural support emerged as one of the foremost themes to meet the support needs of the families living with intellectually challenged children.

5.3.6.1 Basic needs

Some families raised concern over the unmet support for basic needs that would ensure improved care to the children living with ID. In South Africa, ward councillors from local municipalities facilitate provision of reconstruction and development (RDP) houses and sanitation facilities. The study found that ward councillors compile housing and sanitation lists for the needy families and submit to the Department of Human Settlement to provide the services. It is in this regard that sanitation, housing, transport resources and nutritional needs for the child emerged as relevant subcategories related to the main category of basic needs.

The basic needs indicated in Maslow hierarchy of needs are fundamental, including food, water, air, sleep, elimination and shelter, which should be fulfilled before other needs (Morgan & Townsend, 2018:15). The WHO (2011:4) world disability report stresses the need to improve environmental factors, which including safe water, sanitation, nutrition and poverty to enhance the health conditions of PIWD.

5.3.6.1.1 Sanitation

Some families reported lack of sanitation facilities for their children with ID, which affected their daily lives. The following statements reflect the families' dejection with the lack of sanitation facilities to meet the basic health needs of the children with ID:

> *"My child's problem is that we find it difficult to visit because of the toilet facility because we made him a small toilet at home".*
>
> *"We do not have a decent toilet, we are still waiting for the toilets from local government which we made application since long".*

5.3.6.1.2 Housing

Some of the families reported poor living conditions related to poor housing to accommodate the children with ID. Some parents raised concern over lack of adequate housing to accommodate the needs of the children, as indicated below:

> "*I have to go to their room outside the house to check on him and as a woman I am scared and do not feel safe. He refuses to sleep on the floor in my room. I think the RDP house will help me to take care of the child during the night*".

> “*My child sleeps at the shack outside the house. He is not safe. We do not have proper house and do not own our own house*”.

5.3.6.1.3 Transport resources for the child

Families raised the concern that public transport was very expensive, and they could not afford to pay with the disability grant for the child. Most families reported that they kept their children at home owing to lack of transport fees. Consequently, it was also expensive to take the children to school or day care centres. The following statements attest to the concerns with transport:

> “*We have a problem with transport. We were paying transport for R280 and the price increased. It is difficult to take the children to school. Children have many months not attending school. The school fund is R150. My child was attending school but now stays at home*”*.*
>
> “*The school transport is expensive – the child needs to eat and dress. The transport that was provided to take children to school is no longer available and we were not told why it has stopped*”.

5.3.6.1.4 Nutritional needs

Some families mentioned their struggling to just provide adequate food for their children with ID, because most were dependent on the grant of the children. This is attested to by the following statements:

> “*Food must always be available and ready because he cannot tell us that he is hungry. He must just pick up the food and whenever he wants to eat*”*.*
>
> “*My neighbours support him by giving him food. Other problem is that he is not fed by any type of food but usually soft food*”*.*

5.3.7 Improvement Suggestions

As opposed to this chapter’s Section 5.2 (emphasising the participants’ socio-demographic information) and Sub-sections 5.3.1 to 5.3.7 (focusing on a range of the participants’ thematically organised needs), the current Sub-section (5.3.8) focuses specifically on the suggestions made by the participants themselves during the data collection activity. These suggestions relate mainly to the improvement of mechanisms to support children with ID and their families. It is worth noting that, while these suggestions by the participants do not necessarily constitute the recommendations of the study as such, they were taken into cognisance by the researcher in the drafting and consequent development of this study's actual recommendations. In this regard, the integration of the participants' suggestions into the study's recommendations framework also portrays the study's relevance insofar as utilising pragmatic approaches to real-life problems (Julkunen, 2011).

The families suggested strategies to improve and increase the effectiveness of support for children with ID to enhance their ability to cope with the challenges of raising children with ID. Training of families and provision of material resources emerged as the main categories of the improvement suggestions theme.

5.3.7.1 Training of families

The families proposed training on how to cope with the challenges of raising children with ID, which would enhance their capacity to deal with their emotions. The families reported that they just use common sense, but still found it difficult to develop the self-confidence required for the emotional wellbeing of the child. The DoSD (2006:36) also supports the view that training of families facilitates and improves their ability to meet and manage the needs of the children with ID.

5.3.7.1.1 The emotional wellbeing of the child

> The families highlighted that the training would enhance their ability to deal with different emotions and mood disorders displayed by their children with ID. The following participant statements confirm the need for such training: "*You see if we were given information on how to care for the child it will help a lot, it is not right for the child to sit for a long time without any activity. Things like exercises*".
>
> "*The child does not want to stay alone but she needs attention. She will cry even when nothing is happening to her. I mean like crying unexpectedly. I need training on how to treat her properly*".
>
> "*I need more information on how to take care of the child. Especially to manage her when she is angry because of the strange behaviour. I will be happy if they can just teach me so that I don't stress too much*".

5.3.7.2 Provision of material resources

The families advocated for the provision of material resources through government-sponsored initiatives in order to enhance their capacity to cope with the challenges of caring for their children with ID. The particular kind of resources was specified as those that would assist and serve as a strategy to stimulate the growth of the children through multiple forms of activities. In this regard, the provision of a caregiving grant was viewed as a means to achieve an end (availability of material resources).

5.3.7.2.1. Resources to stimulate the child

The families were concerned with activities that the children resorted to in order to keep themselves busy. The following statements attest to this concern, while also strengthening the case for the need for growth stimulating support:

> "*The child likes to dig holes in the garden with a spade. He likes to play with a ball, watching TV, music. He likes something noisy, likes to watch soccer and all kids' programmes. I cannot afford to buy the toys*".
>
> *"We encourage them to play with other children and learn how to play kids games. We have one TV. He cries when we change the programmes".*

5.3.7.2.2 Caregiving grant

The families proposed the provision of caregiving grant to the caregivers of the children with ID. This specific grant was viewed as a parent disability in addition to financial assistance already received in the form of the child disability grant they received each month. As indicated in the below-stated narrative statements, the proposed parent disability grant was justified on the grounds of limited opportunities for employment induced by the demands of caring for their children with ID, including the ongoing struggle to meet the demands of their families:

> "*If the government can pay us grant because some of us were working and we have left the job to care for the children*".
>
> "*There is no enough schools and day care centres to care of the children with disabilities so that we can work. We hope the social workers can organise for us the grant for caring of the child like the one they give it to the elders because we will not be able to work*".

5.4 CONCLUSION

This chapter presented and discussed the predominantly qualitative data collected through the individual in-depth interviews and focus group discussions. This thematically analysed and diagrammatically presented data yielded two categories of information: socio-economic and ID related. The socio-economic data was based on ten variables related to the personal attributes/ characteristics and circumstances of the participants. On the other hand, the ID-related information yielded seven core themes and associated subcategories representing the views and challenges. It was on the basis of these themes, categories and subcategories that understanding was developed about the challenges and support needs of families living with intellectually challenged children. Following discussion of the seven themes, the chapter further presented a discussion on the improvement suggestions made by the participants during the individual in-depth interviews and focus group discussions. Aspects of the reviewed literature were integrated in the discussions to either agree or disagree with the participants. The following chapter (Chapter 6) discusses the research findings in more detail.

CHAPTER 6: DISCUSSION OF THE RESEARCH STUDY FINDINGS

CHAPTER ONE: BACKGROUND OF THE STUDY

CHAPTER TWO: REVIEW OF LITERATURE

CHAPTER THREE: THEORETICAL FRAMEWORK

CHAPTER FOUR: RESEARCH METHODOLOGY

CHAPTER FIVE: PRESENTATION AND DESCRIPTION OF THE RESEARCH FINDINGS

CHAPTER SIX: DISCUSSION OF THE QUALITATIVE FINDINGS

- 6.1. INTRODUCTION
- 6.2. SOCIO-DEMOGRAPHIC RESULTS
- 6.3. DISCUSSION OF THE QUALITATIVE FINDINGS
- 6.4. CONCLUSION

CHAPTER SEVEN: SUPPORT STRAGTEGIES OF FAMILIES LIVING WITH CHILDREN WITH INTELLECTUAL DISABILITY

CHAPTER EIGHT: CONCLUSIONS AND RECOMMENDATIONS OF THE RESEARCH STUDY

6.1. INTRODUCTION

The previous chapter presented and discussed the thematically analysed data emanating from the participants' interviews and focus group discussions. The current chapter presents a discussion of these findings, guided by the themes, categories and subcategories that emerged in conjunction with the researcher's field-based observation throughout the primary data collection process (De Vos et al., 2014: 106). A literature review on the findings was also explored in order to compare and contrast the findings with current knowledge in the sphere of challenges and support needs of families raising and living with children with intellectual disabilities (Donley & Graueholz, 2012:14; IASSIDD, 2014:420).

6.2 SOCIO-DEMOGRAPHIC RESULTS

An examination of the age groups of the participants in this study indicates that the adults bore a greater responsibility in meeting the wants and needs of their children. The findings also showed that the caregivers of the children were middle aged and employable. However, owing to the responsibilities of caring for the children with ID, they were unable to find employment. This resulted in further financial constraints for these families.

Owing to their level of education and experiences with ID, all participants were able to demonstrate a reasonable level of understanding regarding the diagnosis of the children. Most participants were Christians by faith, belonging to different churches, though they were not active members in their faith-based organisations. The family income showed that families were struggling to meet their financial needs, including the special needs of the children affected by ID.

The profile of the children indicated that they were living with other conditions such as epilepsy, further attesting to the continuous and additional care provided by the members of their families. Most of the children were not attending school, but attended nearby day care centres.

6.3 DISCUSSION OF THE QUALITATIVE FINDINGS

6.3.1 The Need for Informational Support

One of the major findings of the study highlighted that there was significantly a need for various aspects relating to the upbringing and care of children with ID. In this regard, the informational needs premised on understanding of the child with ID, management of the behaviour of the child with ID, as well as information relating to the legal rights of children with ID as uniquely privileged individuals entitled to equal human rights enjoyed by families and communities in society (Huus et al., 2016:863; South Africa, 1996:6).

The support needs of families affected by ID necessitated a quest for knowledge that is important for reducing stress and adjusting to the condition of the child (Douglas et al. 2017:2745). However, Davys et al (2014:223) further indicate that insufficient knowledge was a barrier to the families living with children with bodily and intellectual developmental problems. As such, the families found it difficult to engage in future planning on the care of their children living with ID. According to known early childhood development and disability (ECDD) prescripts, services to families of children with ID should aim to provide these families with the knowledge and skills needed to cope with the challenges of raising their intellectually challenged children (WHO, 2012:28).

In South Africa, access to information for self-protection is a constitutional right (South Africa, 1996:13). The White Paper on the Rights of Persons with Disabilities (WPRPD shows that the provision of education on ID instils responsibilities to communities and families in caring for and supporting children with ID (DoSD, 2016:75). It is worth noting that accessibility to relevant information on ID for the families improves empowerment and awareness (King et al. 2017:340). The information portal on ID also provides empowerment to families to understand the needs and condition of the child with ID better (DoSD, 2016:76).

6.3.1.1. Understanding of the child with ID

Understanding of the needs of the child with ID involves different views on the causes of intellectually disability, development of the child, and understanding the limitations experienced by such a child.

6.3.1.1.1. Different views on the causes of ID

The current study established that families lacked understanding on the causes of ID. The existence of the physical problems of the children with ID prompted their families to seek health professional guidance. The families were not able to identify that their children were suffering from ID, until they were informed at the health facilities, day care centres and schools. The ECDD supports this finding in that many children with mild and moderate ID in developing countries were only diagnosed at school age (WHO, 2012:22).

Hence, this causes delays in early treatment and interventions to support the child and the family.

Some families believed that other physical disabilities, such as epilepsy and dry skin, caused the diagnosis of ID. Townsend and Morgan (2018:733) posit that the common ID factors may be genetic, linked to disruptions in embryonic development, pregnancy and perinatal factors, general medical conditions acquired in infancy or childhood and social and other mental disorders. Diagnosis of ID, however, is based on both clinical assessments and standardised testing, which includes intelligence quotient test (IQ). Intellectual and adaptive function and the onset age depend on the severity of the brain dysfunction (APA, 2013:38).

6.3.1.1.2. Development of the child with ID

The study has shown that the families' lack knowledge on the developmental needs of the children with ID and their low functional ability caused frustrations and challenges for their families, who lacked the ability to accommodate for the slower developmental milestones of the children. Some have shown that the development of the children was fluctuant, which contributed to the families' inability to identify the early features of ID. The families had expectations of normal growth and development for their children with ID and compared them to their peers, who had normal developmental milestones.

The study by Paliwal and Paliwal (2014:1439) has shown that ID adversely affects the child at different levels of their development. According to the American Psychiatric Association (2013:31), ID or intellectual developmental disorder (IDD) is a neurodevelopmental disorder with excesses or deficits and delays in achieving expected milestones.

6.3.1.1.3. Limitations of the child

The current study has shown that some families were not able to understand that their children were not able to perform other activities on their own. The families expected the children to be responsible and develop a sense of right and wrong. Children were not able to perform developmental skills, including self-grooming, toilet habits, feeding, and cognitive skills. Communication was the major cause and barrier for some families in understanding the needs of the children. The poor development of communication skills makes it difficult for the children to express their needs to their families.

Townsend and Morgan (2018:735) state that children with moderate ID with an intelligent quotient of 35-49 may experience limitations in verbal communication. According to the American Psychiatric Association (2013:38), lack of communication skills may predispose the children with ID to disruptive and aggressive behaviours.

6.3.1.2. Information on management of behaviour of the children with ID

Information on the management of behaviour of the children with ID was necessitated by their challenging behaviour, social interaction and discipline measures in consideration of their ID condition.

6.3.1.2.1. Challenging behaviour

The findings have shown that families were not able to understand and manage the behaviour of the children with ID. Some of the challenging behaviours reported by families were defiance, disruptiveness, stubbornness, tendencies to roaming around, running away and overeating. Aggressive behaviour was the main barrier between the children with living with ID and their siblings. The behaviour was reported to escalate when the children could not get what they wanted. The study of Wieland, Ellingsen and Baker (2014:28) posits that the behaviour of the child with ID depends on the developmental level of that child. However, Dandashi, Karkar, Saad, Barhoumi, Al-Jaam and Saddik (2015:1) posit that aggressiveness in children with ID relates to poor social adjustment.

In line with these findings, the study by Ng and Rhodes (2018:149) found that physical aggression was the most notable behaviour of children with ID. The aggression was difficult for the families to manage and resulted in fear for the safety of the siblings. The American Psychiatric Association, (2013:40) notes that children with more severe ID may exhibit aggression and disruptive behaviour that may harm others or destroy property. Ruddick, Davies & Bacarese-Hamilton (2015:10) also found that aggression was rated as the behaviour that most difficult to manage in children with ID.

6.3.1.2.2. Social interaction of the child

Participants expressed that children with ID found it difficult to socialise and interact with some of the members of the family and community. Some families reported that the children refused to play with other children or to visit other extended family members, including elder siblings. Townsend and Morgan (2018:734) assert that the nursing diagnosis of children with ID includes impaired social interactions, stemming from underlying speech deficiencies, or difficulty to adhering to conventional social behaviour.

The ECDD concurs with the findings by indicating that the mothers and caregivers of the children with ID dominate interactions more than other people do (WHO, 2012:14).

6.3.1.2.3. Discipline of the child with ID

The findings have shown that some families were unable to discipline the children with ID when they exhibited inappropriate behaviour. The children were reported to be disrespectful to some family members and did not follow the expected family norms and values expected of them. The findings of Uys and Middleton's (2014:548) study resonate with this study's findings in indicating that the families often find it difficult to discipline the children with ID. However, the children need to learn desired behaviour. Dandashi et al. (2015:3) stress the important of reinforcement and punishment to encourage good behaviour of the children with ID.

6.3.1.3 Information on the care of the child with ID

Information on the care of the child with ID was necessitated by factors such as overprotectiveness and safety of the child; attachment to caretakers; and medical care for the particular child with ID.

6.3.1.3.1. Overprotectiveness of the child

The study findings have shown that some families display overly protective behaviour towards the children with ID. In other cases, some families protected the children with ID more than other siblings and family members. The needs of the children with ID got first preference in the families and some participants even mentioned that they felt sense of guilt for paying unequal attention to the needs of other siblings.

The previous study of Aydin and Yamac (2014:90) support these findings by positing that the struggle of the children with ID on both social and psychological adaptations might influence the family to exhibit overprotectiveness. Hence, some families projected with over mothering attitude as revealed in this study. Similarly, Irazabal et al. (2016:120) findings congruent to this study, found a negative impact with care and overprotectiveness and mutual dependence between the primary caregivers and the children with ID. Uys and Middleton (2014:548), support that the families overprotect the child with ID owing to the fact that they feel sorry for the child.

6.3.1.3.2. Safety of the child

Most families expressed concerns on the safety of the children with ID. Lack of trust in people and the environment around their children with ID were raised as major problems to the families. One family has reported that their child was sexually abused by the other learner while at school. However, the matter was reported to the police but the case was never followed up by the police officers and the school. The ECDD identified the need for the children and their families to be able to access child protection systems owing to the vulnerability of the children (WHO, 2012:25).

The wandering and running away behaviour of the children posed dissatisfaction of the families on the safety of the children. The results highlighted that the families were not able to understand the behaviour of children with ID and decided that the best way to protect the children was to keep them under lock and key at home. However, the safety concerns restricted the social life of the families, as they have to watch the movement of the children on full time basis. Congruent to this finding, the study of Robert et al. (2014:175) confirm that families play active role to ensure protection and defend the children.

The ECDD has shown that children with ID are more vulnerable to abuse and exploitation than typical developing children (WHO, 2012:16). The American Psychiatric Association, (2013:38) opine that ID is associated with gullibility, lack of assessment, and poor risk awareness. Furthermore, these may result in mistreatment by others, possible victimisation, unintentional criminal participation, untrue confessions, and risk for physical and sexual maltreat. However, the study of Robert et al., (2014:175) support these study findings by revealing that parents are key players in protecting the children with ID.

6.3.1.3.3. Attachment to caretakers

Some families reported that they feel more comfortable to take care of their children with ID on their own. They further expressed that children complained when under the care of other people, including teachers and they feel they are responsible for the child’s safety. The children were dependent on the care of their family members.

According to the Attachment Theory, a child develops a schematic attachment demonstration that is dependent upon parental interactions based on the level of love, acceptance and respect they receive from the family (O’Neill & Murray, 2016:3145). However, the affective bond that develops between the child and the regular caregiver mostly affects the social interaction of the child with other family members. Hence, the child withdraws and feel uncomfortable or unsecured when the caregiver is not available (Butcher & Gersch, 2014:2). These study findings were consistent with the study findings of Yang, Byrne and Chiu (2016:52) indicating that parent-child attachment mostly base on time spent and experiences shared with children with ID. In the same vein, Irazabal et al. (2016:13) found that mothers were quite attached to self-image of sacrificing their well-being needs to the helpless child with ID.

6.3.1.3.4. Medical care of the child

The findings have shown that most of the children with ID were living with chronic conditions, including, epilepsy, autism, and Down syndrome (Yang, Byrne & Chiu, 2016:52). Some children with epilepsy were reported to have experienced the attack of epileptic seizures irrespective of taking anticonvulsants especially during the night while asleep, hence this experience required medical attention. Families did not take the children to health services for consultation due to lack of information on the effect of seizures to the health of the children.

The literature has shown co-occurring medical, physical, and neurodevelopmental conditions, including, epilepsy, cerebral palsy and autism, which are common in children with ID (APA, 2013:40). The National Mental Health Policy Framework and Strategy posit that in cases where comorbidity exists with ID, the care and treatment is the responsibility of the Department of Health (DoH, 2013:10).

Wakimizu et al. (2017:44) indicate that the provision of medication to the children with developmental problems will improve their health status and functioning ability. The ECDD support the findings by indicating that children with ID are at risk of developing secondary childhood conditions and often require specialised health care needs (WHO, 2012:23). However, Moeschler and Shevell, (2017:913) recommend that all PWID must undergo comprehensive medical evaluation by medical and genetics specialists.

6.3.1.4 Information on stimulation of the child

Information on stimulation of the child with ID centred mainly on development of self-care, language and cognitive abilities.

6.3.1.4.1 Self-care development

The findings by APA, (2013:40) have shown that the families were doing everything for the children with ID. The children were not encouraged to learn how to perform basic self-care activities, including feeding, grooming and toilet training because family members who happened to be the caregivers, thought that the children’s learning capabilities were very low or non-existent. Some families were feeling that the children take time to complete small tasks. Moreover, self-care activities, including motor skills, feeding skills, dressing and undressing and toilet training are identified as effective to stimulate the children with ID (Uys & Middleton, 2014:559). Furthermore, the study findings indicate that families were not willing to engage the children to the activities owing to the limitation in self-care and potential hazards that might occur. Moreover, lack of stimulation in daily living activities of the children exposes them to physical health risks including, weight gain and poor health (Gauthier-Boudreault et al, 2017:23). However, the involvement of the child with ID in physical activities reduces health risks, including obesity (Dandashi et al., 2015:3)

6.3.1.4.2. Language development

The families reported that the children have difficulty in expressing themselves to meet their daily needs. They reported to be crying and showing anger if the family members were not able to understand what they are looking for. Some raised a concern that the children cannot initiate any communication with siblings and that created a barrier between them.

The study conducted by Cenk et al. (2016:708) found that PWID experience slow language problems that affect their expression of speech in which children fail to make their needs understood by people around them. Therefore, lack of stimulation often results in poor social interaction and in which the child with ID is not willing to interact with siblings and peers, as a result, this led to isolation exposing the children to lack of activity resulting in weight gain (Gauthier-Boudreault et al., 2017:23). Congruent to this finding, the study of Donohoe, Bornman and Granlund (2015:404) assert that lack of language exposure to intelligible speech to children with ID, affect the child’s cognitive development.

6.3.1.4.3. Cognitive development

Dandashi et al. (2015:3), revealed that most families lacked knowledge on how to stimulate the cognitive development of children with ID. They were not able to involve the children in the activities that will develop their learning and thinking ability. However, they were concerned about the slow progress of the children compared to their peers with typical development. Involving children with ID on activities including playing games is necessary to stimulate and improve cognition and concentration abilities for better development (Dandashi et al., 2015:3). Therefore, it is imperative for the families to be encouraged to perform all sorts of activities and exercises to stimulate cognitive development of the children with ID (Robert et al., 2014:17).

6.3.1.5 Information on the legal rights

Information on the legal rights of the child with ID also incorporates the rights of their families as members of communities and society. As such, the ID condition of their child/ren does not in any way deprive them of all the rights and benefits accruing to all citizens.

6.3.1.5.1. Rights of children with ID

The families are of the opinion that children with ID do not have the rights. Caregivers of children with ID are the guardians of children's rights (Huus, Dada, Bornman & Lygnegård, 2016:863), however the study findings revealed that families had inadequate information about the rights of children with ID. They indicated only the rights that they were able to practice as family members. The ECDD posits the rights of children with ID as the right to survival, protection to harmful effects, maltreatment and exploitation, engagement to family activities such as meetings and family functions, including cultural and social life (WHO, 2012:8).

The UNCRPD commits every country to respect and implement the rights of PWID (DoSD, 2016:20). The South African Human Rights Commission (SAHRC) hosted a National Conference on the Rights of Children with Disabilities to strengthen the relationship with NGOs and government departments to ensure inclusive society to raise children with disabilities (SAHRC, 2013:17).

The WPRPD indicates that children with ID have social rights to education, healthcare services, housing, transport, recreation, culture, communal development, nourishment security, and family life (DoSD, 2016:46). The findings of this study correlates with those of the study of Huus et al. (2016:867) who also found that the caregivers of children with ID in rural areas in South Africa, were having less information on the rights of the children with ID. Furthermore, Adithyan, Sivakami and John (2017:91) mention that it is imperative for caregivers and families to be informed about the rights of children with ID, this will enable them to be able to protect them within their rights.

6.3.1.5.2. Rights of the families of the children with ID

Limited knowledge and insufficient information on the rights of raising the child with ID, made life difficult for families to raise children with ID. However, some were able to indicate their needs as the rights, furthermore, the WPRPD indicates that lack of knowledge on legal rights causes a barrier to access justice system when wronged (DoSD, 2016:78).

The families reported inability to access basic service delivery including sanitation. The researcher also observed that some families were living in poverty. According to DoSD (2001:13), the framework policy on families indicates the rights of families including, independence, service delivery, development, protection from poverty, employment opportunities, freedom from abuse and exploitation, harmless environments and healthy well-being.

6.3.1.6. Information on the services available

Information on available services apply to both the children with ID and their families.

6.3.1.6.1. Services available for the child with ID

Most children with ID were reported to have problems that required health care services such as, medical services where they were to consult with general practitioner, physiotherapist, social workers, speech therapists, ophthalmologists, dentists and ear, nose, and throat specialists (ENT) and psychiatrists for behavioural problems. The findings of the study revealed that the families had inadequate information on the services offered by the professionals to assist with the care of children with ID. Some families were able to access the services only when children were hospitalised. Lack of information and continuous in-hospital health education and information about the post admission referral system, the family do not proceed with community services available to children with ID, which are almost similar to the services provided to them in-hospital.

The ECDD posits that children with ID often miss to mainstream services including, essential vaccination and treatment for common childhood illnesses (WHO, 2012:17). The study findings are consistent with the study of Fujioka, Wakimizu, Tanaka et al. (2016:1737) indicating that the care for children with ID includes control of seizures, muscle tone and other problems. The World Report on Disability strongly stresses the reforming policy and legislation to ensure the availability and affordability of treatment services close to the communities in which children with ID live (WHO, 2011:65).

The study of Masulani-Mwale et al. (2016:876) found that the inability of most parents to access better services for their children with ID, including special schools and after care services make them to feel discriminated from others. Congruent to these study findings, Gilson et al. (2017:356), found that familiarity of the families with the available resources to children with ID was limited. However, the instability of the condition of children reduced interaction of the families with other community members.

6.3.1.6.2. Services available for the families

The study by Masulani-Mwale et al. (2016:874) found that most parents reported lack of accessible facilities to seek help for their own psychological problems, which have resulted in mental problems including, parental stress and depression. Most families were experiencing family problems that needed multidisciplinary team (MDT) services but were not able to identify those problems that needed professional interventions, which can only be the result of an internalised depression, or they had lots of problems whereby, they are unable to talk about them anymore. Hence, professionals working with families with children with ID have a responsibility to monitor stress and psychosocial problems and refer them for support in a timely fashion for better health (Kleefman, Reijneveld & Jansen, 2015:55). The WPRPD posits that the government has a responsibility of providing services, including education, food subsidies, health care, and subsidised housing to the citizens who are not able to afford them (DoSD, 2016:27).

6.3.2 The Need for Professional Support

Mas et al. (2016:69) indicate that professional support plays an important role to provide the families the opportunity to comprehend and develop the strategies to adjust to the new reality of having to raise the child with ID. The findings of the study have shown lack of professional support to the families raising the child with ID. (Jansen et al., 2012:433) intimate that parents continuously evaluate the support services provided by professionals in terms of accessibility and availability when needed. However, McKenzie, Mayer, Whelan, et al. (2017:60) study found that support services provided by the professionals were against them and did not meet their support needs leading to disagreements.

6.3.2.1. Collaboration between families and professionals

Collaboration between families and professionals also involves frequency of such interaction in order to monitor the progress of the child with ID and determine the future course of support services and referrals where necessary.

6.3.2.1.1. Communication between families and professionals

Families reported negative experiences related to poor internal communication with professionals. No feedback was given to the families regarding the progress of children with ID by teachers except the fact that families were constantly reminded that their children were slow learners. In addition, the health care providers such as school health nurses, also blamed the school for not referring children for proper assessment, which leaves the family with nobody to talk to about the child's progress at school. This resulted in most children with ID not able to attend school or day care centres.

Modula and Ramukumba (2018:10) mention that communication skills believed to create therapeutic environment that enables clients to open up and able to express their feelings to the professionals. Jansen et al. (2017:60) emphasise the fact that exchanging information about the child between the family and professionals enables the evaluation of new intervention and further family referrals for specialists' services. However, Al-Kandari (2014:120) argues that the families also have a role to share information of their needs with professionals while professionals listen and solicit presented information to plan accordingly for the needs.

6.3.2.1.2. Frequency of contact with professionals

The families were concerned that the services caring for the families were not a walking distance and reported to have problems when visiting the facilities for advice and information. The findings revealed communication breakdown between health professionals and educators with regard to health and education. Some of the families reported that children were experiencing medical problems, which required intervention of the professionals but they were also not willing to consult for intervention. However, Douglas et al. (2017:2739) found that health professionals particularly nurses and midwives play a crucial role at the diagnoses of ID of the child and should take a lead to empower parents through the process of adjustment. In addition, the World Disability Report indicates that health care providers' attitudes can contribute to negative experiences of the health system and common barrier to seek necessary services by the families (WHO, 2011:77). The study of Wilkins, Leonard, Jacoby et al. (2010:715) are congruent to these study findings in indicating that the frequency of contact with allied health care professionals enhanced positive parental perceptions towards care of their children with ID.

6.3.2.2 Referral to relevant services

Referral to relevant services involve professional assistance and consultations for mental health, speech and hearing, and psychological attention and observation at either PHC, local government and social work centres or facilities.

6.3.2.2.1. Mental health services

The study findings revealed the need for mental health services for the families to be able to cope with the care of children with ID. Family members have indicated that they felt depressed and cannot enjoy life owing to the impact of the care of children with ID. Furthermore, the study indicated the signs of withdrawal in families to interact with the community members. One parent reported thoughts to commit suicide owing to the inability to cope with the demands of raising a child with ID. The findings of this study resonate with Hooda and Gupta's, (2017:573) study, which found that the primary caregivers of children with ID experience less psychological wellbeing. In support of the findings, the World Report on Disability emphasises that timely referral to relevant services by the professionals can facilitate access and reduce stress and frustrations therefore decreasing exposure and risks to secondary conditions (WHO, 2011:77).

Masulani-Mwale et al. (2016:875) concurs with the findings of this study when they found that suicide was one major mental issue attributed to divorces resulting from raising the child with ID in Malawi. Furthermore, Irazabal et al. (2016:13) also affirm that families of children with ID usually experience mental health problems related to stress of caregiving. In essence, the family needs emotional support from mental health professionals as formal support service to enhance their FQOL (Samuel, et al., 2012:113). Moreover, the families can endure tremendous pressures mentally in their lifelong career of raising children with ID (Pan & Ye, 2015:359).

6.3.2.2.2. Speech and hearing services

Donohue, Bornman, and Granlund (2015:403) posit that language problems can be the result of cognitive growth. Hence, families lacked information to access the necessary services to assist their children. Families reported that some children experienced problems in hearing and expressing their needs to the family members. Some further elaborated that children became angry and frustrated when family members were not able to understand them, owing to the speech problems.

The study of Balcells-Balcells et al. (2019:55) corroborated the current findings that most families requested speech or language support. The WPRPD emphasises that it is the right of every child with communication and hearing problems to be able to access assistive devices to increase their independence (DoSD, 2016:98). King et al. (2016:336) posit that training programmes for families on augmentative and alternative communication to participate on therapeutic role enhances the communication of the child. Congruent to this finding, Hewitt et al. (2015:162) note referral of the children with ID to speech therapies to improve the communication ability.

6.3.2.2.3. Psychological services

The need for psychological services raised as a support need when families reported anxiety and stress related to the future of the children regarding self-care and the demanding care needed for the children with ID. The study revealed that most families found it difficult to adjust and accept the challenges of raising the children with ID. Balcells-Balcells et al.'s (2018:57) study resonate with the current study results and indicate that the presence of the child with ID could affect the psychological health of their family members.

It is noteworthy that the increased psychological mental pressure experienced by the families living with the children with ID may compromise the expression of enthusiasm towards their care (Su, Cuskelly, Gilmore & Sullivan, 2017:1179). In support of this study, Akturk and Aylaz's (2017:351) findings posit that families with children with both intellectual and physical disability be provided with more psychological support to relieve anxiety. Furthermore, Kumari (2017:362) found that psychological services provide a coping strategy and motivation that can reduce stress related to raising the child with ID.

6.3.2.2.4. Community primary health care services

The study findings revealed that some families living with children with ID were not able to access support services from the health providers available to the communities with needs. The families of children with ID felt rejected or ignored by health system. They indicated that they always see community providers from NGOs providing support services to the families with other chronic conditions, including HIV excluding them. However, Integrated National Strategy on Support Services (INSSS) to children with disabilities revised draft posits that primary health care providers are not trained to work with families and children with disabilities (DoSD, 2009:15). Furthermore, the inclusion of ID in primary health care services will promote integration and provision of support services including effective referral at the community clinics (Capri, Abrahams, McKenzie et al., 2018:10).

It is noted that health care workers themselves, lack proper skills and knowledge to address the needs of children with ID and their families, as a result, families feel rejected by the whole system hence, the World Disability Report stresses the importance of including ID in education and training for health workers and educators (WHO, 2011:78).

The study evaluating the implementation of White Paper on Families in South Africa has shown that lack of resources and staff turnover are barriers to effective training programmes of health care providers leading to poor services to the families in need (Patel, Hochfeld & Englert, 2018:23). This was a concern to the families of children with ID that they felt neglected by the health care services. Congruent to these findings, Balcells-Balcells et al. (2018:57) found that the health staff had insufficient training to equip them with skills to provide support to the families of children with ID.

6.3.2.2.5. Local government services

Some families raised concern over inadequate contact with the responsible local councillors to attend to their challenges of living with children who have ID. They reported long waiting periods for the municipal services with poor feedback regarding housing and sanitation facilities. The INSSS for Children with Disabilities Revised Draft corroborates the findings of this study by indicating that national and provincial departmental policies on directing care of disabilities, depend mostly on the implementation approach of local municipalities to provide effectives services to the communities (DoSD, 2009:16).

Municipalities should keep the register for persons with disabilities who are legible for housing subsidy, for providing them with priority services (Foskett, 2014:25). However, the services include transport, justice and security to protect the rights of children with disabilities.

6.3.2.2.6. Social work services

Families had challenges with support from the available social work services which was not helpful for them. This created a barrier in which some of the families indicated that the social workers judged them with regard to the care of children with ID, as a result, they reserved all the comments and responses regarding the child with ID. Even though, families experienced social problems that needed interventions of the social workers, they never reported such challenges with the fear of being blamed for every challenge they have.

Ai-Kandari (2014:122) opines that social workers should seek social justice to empower parents of children with ID by responding to their needs, understanding their situation and provide support. However, the Limpopo Strategic Plan for 2015-2030 acknowledges the gap to ensure attention and support to needy families owing to the shortage of social service professionals (DoSD, 2013:17).

6.3.2.3. Counselling services

As a means of support to families of children with ID, counselling services involve genetic couple counselling, sibling adjustment, co-parenting and adjustments for improving the quality of marriage.

6.3.2.3.1. Genetic couple counselling

Counselling information on ID to enhance health by reducing parental stress is essential (Douglas et al., 2017:2774). The study findings have shown the need for genetic couple counselling for some families where fathers were blaming the mothers and maternal families for the diagnosis of the child with ID. Some families especially mothers reported that their partners were not supportive but instead blamed them for the disability of children. Hence, this study shows the important of the couples to receive counselling to be able to understand the causes of ID. Duran and Ergün's (2018:394) findings resonates with the findings of this study and indicated that others were blamed by their spouses for the ID children instead of supporting them. Therefore, counselling information on ID to enhance health by reducing parental stress is essential (Douglas et al., 2017:2774). In support of this study results, Moeschler and Shevell (2014:913) stress the importance of genetic counselling services to confirm the clinical diagnosis of children with ID as a source of information to the families.

In support of this study results, Moeschler and Shevell (2014:913) stress the importance of genetic counselling services to confirm the clinical diagnosis of children with ID as a source of information to the families.

6.3.2.3.2. Sibling adjustment

Some families reported that some of the siblings were not accepting children with ID as their brother or sister. These study findings indicate that some families expected the siblings to assist in child-care as a relief for parents or caregivers of children with ID.

However, some participants expressed that the siblings compromised the time needed to take of the child with ID. Therefore, families found it difficult to involve the siblings actively in the care of the child with ID. Some of the sibling were reported to be feeling embarrassed by the condition of the child with ID.

The study of Shivers and Kozimor (2017:10) found that the siblings of children with ID experienced anxiety, hostility and depressed feelings or dysphoria towards their family member. However, Kaur (2015:1033) supports that the present of child with ID in the family highlights the beginning of a journey that requires adjustments time by the whole family. In addition, Povee, Roberts, Bourke and Leonard (2016:222), Jacobs and MacMahon (2016:13), emphasise the need to support the siblings as they play an important role in the lives of their family member with ID.

Ng and Rhodes (2018:150) study, in support of the current findings, found that the physical and mental well-being of the siblings were compromised and further argued that this is the main reason for some families to decide relinquish of the siblings out of the home to boarding schools. Therefore, families reported that some siblings were not willing to assist their brother or sister with ID. However, the study findings of Adithyan et al. (2017:85) posit that families who accept the condition of their child with ID develop positive attitudes towards the member.

6.3.2.3.3. Co-parenting

Mothers showed frustrations of dealing with the children's' challenging behaviours without the presence of the fathers, this was reported by mothers who were unable to handle the situation of looking after children with ID because fathers were inactive and distanced themselves from the care of the children with ID. Mothers showed frustrations of dealing with the children's' challenging behaviours without the presence of the fathers. Co-parenting of the child with ID was emphasised by social development services' practitioners as a way to assist parents to go through the struggle of raising the child together. The mothers explained the fathers' roles as that of providing finances to meet the family basic needs The findings were supported by the findings of the study of Jeong, Siyal, Fink, McCoy and Yousafzai, (2018:8) revealing that fathers had the responsibility of financing doctors' visits and purchasing medicine while mothers were taking care and monitoring the child's status.

In support of this study, the findings of Cohen, Zeedyk, Tipton, Rodas and Blacher (2016:304) United States of America found lack of presence of spousal relationship and support to handle the challenging behaviour of the children with ID. In addition, the study of Boström and Broberg (2014:819) revealed that the fathers' adaptation to cope with the challenges of raising a child with ID affects them negatively compared to mothers.

6.3.2.3.4. Marital quality and adjustment

The results of the study have shown that families of children experience marital problems. Some parents reported to be divorced after the diagnosis of the child. In most cases, the parents blamed each other on the genetic causes of the condition of the child. Those still married raised concerned that their partners were having extramarital affairs and were unhappy about their marriage life. Hence, the presence of the child with ID brought negative changes to their marriage.

Norton, Dyches, Harper, Roper and Caldarella (2016:3701) report that the divorce rate is higher in families who raise children with ID especially within the first two years of the birth of the child, which is the stressful time for adjustment. The fact that most mothers were sleeping with their ID children in one room irrespective of the age of the child have shown that the couple found it difficult to have intimacy. In consistent with the findings of this study, Povee et al. (2012:970) also found that added pressure of caring for the child with ID result in lack of intimacy among couples, contributing to marital conflicts.

6.3.2.4. Family-centred interventions

Family-centred interventions involve parenting and problem-solving skills, family empowerment, adaptability to change, education of the child and quality of parenting.

6.3.2.4.1. Parenting skills

The families reported to be having a problem when they have to manage the behaviour of the children with ID and needed training on parenting skills. The Family and Parenting Support Policy (FPSP) posits parenting skills as a set of activities directed to improve how parents approach and carry out their role towards child rearing resources and capabilities (UNICEF, 2015:12). The Family and Parenting Support Policy focused on imparting information, education and skills for rearing of the child (UNICEF 2015:8). In addition, Harnett, Bettendorf, Tierney, Guerin, O'Rourke and Hourihane (2013:413) posit that the way professionals disclose the diagnosis of the child may have negative impact on the parents.

The main focus of the need for parenting skills is to encourage the parents to develop skills for managing difficult behaviour as well as building more positive behaviours of the children with ID (Families Special Interest Research Group of IASSIDD, 2013:424). It is noteworthy that positive parenting skills improve parent-child relationship (Agazzi, Tan, Ogg, Armstrong & Kirby, 2017:285). The previous study of O'Neill and Murray, (2015:3150), argue that the negative parenting style was inevitable consequences of the parent having to deal with extra demands of children with ID.

6.3.2.4.2. Problem solving skills

Families were unable to deal with their own issues, as a result those issues lead to unresolved conflicts and sometimes in worse case scenarios, they change to domestic violence. Mothers, blame fathers that they were not participating actively as a unit in decision-making regarding the care of the children with ID. According to Marquis and Huston (2017:3), problem solving is a systematic operation focused on analyses to be able to identify the root cause of a difficult situation to make a decision. In support of these findings, problem solving as adaptive coping strategy enables the individual to view the situation objectively and take the initiative (Townsend & Morgan, 2018:9). Therefore, problem solving is a skill that requires learning and experience of an individual.

6.3.2.4.3. Family empowerment

Family empowerment includes attitudes, behaviours, knowledge and skills to navigate access to the necessary support services (Caldwell, Jones, Gallus & Henry, 2018:374). The results revealed lack of family empowerment programmes from professionals to encourage them to participate actively in the care of the children with ID. Families had inadequate skills to manage the child with seizures, speech problems and hearing problems. Family empowerment includes attitudes, behaviours, knowledge and skills to navigate access to the necessary support services (Caldwell, Jones, Gallus & Henry, 2018:374).

Fujioka, Wakimizu, Tanaka et al. (2015:1738) found that empowerment improves the ability of the family to continue using services through cooperation with professionals. Though parents are teachers by nature, transferring knowledge to them by the professionals indicated positive impact regarding the care of the child with ID (Cenk et al., 2016:707). However, it is noteworthy that family empowerment during transition of raising the child with ID, can be used by the professionals effectively to enhance family resilient (Caldwell, Jones, Gallus & Henry, 2018:384).

6.3.2.4.4. Adaptability to change

Some families gain personal growth through their religious beliefs to be able to adapt to the changes brought by living with the children with ID. In most cases, change is difficult and affects people in different ways, however most families showed difficulty in adapting to the demands of caring for the child with ID. Consequently, the family needs to plan accordingly in order to be able to prepare and organise the environment to suit the needs of the child with ID. According to Manor-Binyamini (2016:102), adaptability to change indicates the ability to be flexible to face new reality. Furthermore, the high level of adaptability to change in the family of child with ID shows the high perception of emotional support and personal growth among the family members (Manor-Binyamini, 2016:102).

6.3.2.4.5. Education of the child

The Bill of Rights chapter 2 in the Constitution of South Africa stipulates that every child has the right to access basic education (South Africa 1996:12). In addition, the study of Huus, Dada, Bornman and Lygnegård, (2016:868) support that high number of children with disabilities in South Africa were not attending schools. However, the Draft Learning for Children with Severe and Profound ID, (2016:9) emphasises that education and training development of children with ID increase their capacity for communication and self-care skills. The study found that most children were not attending schools or after care. Some families were not willing to arrange for the children to receive education or stimulation. The families reported that children were suffering from co-morbidity conditions such as speech and hearing problems contributed to the families been reluctant to take children to school. These study findings are congruent with the study of Krajnc and Seršen, (2017:12) in which the families complained that they were not able to receive the progress report of the children with ID from special schools.

6.3.2.4.6. Parental efficacy

Some families reported lack of confidence regarding the care and raising of a child with ID. Most families were concerned about their knowledge to provide effective care for the children with ID. Some families reported not to be trusted by the members of the community on the care they provide to their children with ID. Cohen, (2013:74) posits that self-efficacy is an individual’s belief about own competency to perform parental role irrespective of the challenges emerging. However, Chien, Rodger and Copley, (2017:491) support these study findings that the high level of parental efficacy contribute to great enjoyment of children to participate during activities and high sense of personal development.

In addition, the study of Su, Cuskelly, Gilmore & Sullivan, (2016:1180) found that parental efficacy predicts parental warmth and greater authoritative parenting. Moreover, Jess, Hastings & Totsika, (2017:934) argue that parental efficacy showed to be stronger in maternal positivity by reducing stress and child behaviour problems.

6.3.2.5. Home visits

Home visits are crucial for family therapy, family coaching and coping strategies of both the family and the child with intellectually disability disorder.

6.3.2.5.1. Family therapy

Some families experienced family instability, as a result, they were unable to identify the real cause. The goal of family therapy is to promote change and improve adaptive functioning within the context of the family. However, this is possible through identifying, understanding and assessment of family problems and dynamics between the family members (Townsend & Morgan, 2018:208). Visitation by professionals was crucial at this stage, to identify the families' strengths and weaknesses. Furthermore, the visits will enable intervention accordingly and facilitate decisions on appropriate referrals regarding their problems.

Family therapy educates family members and assist them with coping mechanisms to help them understand and develop coping strategies to meet the challenges of caring for the child with ID (Townsend & Morgan, 2018:214). However, Keltner and Steele, (2019:109) argue that family therapy is the responsibility of qualified professionals. These professionals include social workers, marriage and family therapists, psychologists and advanced psychiatric nurses.

6.3.2.5.2. Family coaching

The findings of the study have shown the need for coaching for better competency of the families on the care and management of the children with ID. Families were not sure of the efficiency of the care and support they provide to their children. Furthermore, the findings showed the need for coaching as a spontaneous teaching strategy to empower the families to attain optimum level of performance in raising the children with ID (Marquis & Huston, 2017:425). Hence, the study findings of (King et al., 2017:345) congruent with these study findings have also shown that coaching interventions were meaningful to assist the families to feel competent with the care of the children with ID.

6.3.2.5.3. Coping strategies

Many families have developed their own coping strategy of accepting that there was nothing to change the situation. However, some acknowledged that living with the child would never be easy to their lives but made peace with it. The study found that the families have acknowledged the fact that living with the child with ID had difficulties and challenges. Most families endorsed that acceptance was the main reason to keep them coping with the burden of caring for the child with ID. However, the researcher has observed during the interviews that acceptance of the families could be regarded as avoidance strategy to express their disappointment. Consistent with these study findings, Akturk and Aylaz, (2017:351) found that children with ID constitute a hard-to-accept situation to their families, especially parents.

A coping strategy refers to a specific approach used to control stress, which can emerge naturally or learned (Kosslyn & Rosenberg, 2014:395). Morse and Johnson (1991 cited in Morrison & Bennett, 2012:419) showed that most families were affected by receiving a diagnosis of a long-term life threatening of the child. Furthermore, the families have to learn coping skills to be able to manage difficult situations and further required emotion-focused coping approach in order to be able to change their emotional responses to live with the children with ID.

6.3.3. The Need for Psycho-Emotional Support

The results have shown lack of psycho-emotional support services to the families of children with ID. The need for self-care management emerged as category for this theme. Kyzar, Turnbull, Summers, and Gomez, (2012) define emotional support as assistance of increasing psychosocial functioning to reduce stress and improve inclusive positive orientation to life. In addition, on-going emotional support is crucial to assist parents with adjustment and the opportunity to work through their emotions and uncertainty (Aldersey et al., 2016:28; Douglas et al., 2017:2740).

A study conducted by Cenk, Karayagiz and Sarlak (2016:708) concurs with the findings of this study in asserting that increase in emotional support diminishes the family burden of raising the child with ID. The Europe Report on Better Health, better lives of children and young people with ID and their families corroborates the findings of this study by indicating that provision of psychological support to parents immediately after the birth of the child will influence parents to keep the child in the family than institutionalising (WHO, 2010:13). It is noted that the higher the levels of emotional support, the higher the ability to adapt to change and the higher the levels of personal growth of the families raising the children with ID (Manor-Binyamini, 2016:104).

6.3.3.1. Family self-care management

Family self-care management is a factor of psycho-emotional support, and involves stress management, hopes, fears and uncertainty concerning the future of the child with ID.

6.3.3.1.1. Stress management

The study findings revealed that families experienced stress resulting from caring responsibilities of their children with ID. Spending more time focusing on activities of the child, aggravated the stress of family members, as they were not able to attend to social activities to relieve stress and tension related to the burden of caring for the children with ID. Townsend and Morgan (2018:8) indicate that the first step in stress management is awareness of the stressors to be able to develop stress response feelings.

Families who keep their children at home has elevated stress level than those who were attending school. The findings of this study are consistent with those of the study by Chouhan et al. (2016:503), which confirmed that families living with children with ID experience high levels of stress which increases with the severity or complications of ID. However, Yang, Byrne and Chiu (2014:53) argue that the extra efforts of families to fulfil family expectations to the learning ability of children with ID also contribute to the stress and disappointment. Moreover, the involvement of coping strategies is important in managing stress (Townsend & Morgan, 2018:8).

6.3.3.1.2. Hopes for the future

Most families indicated their main wishes and hopes for the future of the children with ID was to be able to learn skills that will help them to be independent and to be able to provide for themselves. They emphasised the importance of learning centres to train their children for career skills. In support of these study findings, Sandhu, Ibrahim and Chinn, (2017:378) mentioned that education services would be the source to improve their educational services that would change the children’s lives.

The findings revealed that parents had hopes about the future of their children and their focus was the life skills to develop the children. However, Robert et al. (2014:174) argue that families of children with ID distanced themselves from investing much in the future knowing that the condition will never change. Moreover, the study of Cenk et al. (2016:708) found that hopelessness depends on the degree of the disability of the child and how much knowledge does the parent have regarding prognosis, furthermore young mothers were more hopeless than older mothers who were less educated.

6.3.3.1.3. Fears and uncertainty about the future of the child

Family members especially mothers showed great concerns, fears, and hopelessness about the future of their children with ID in case they die leaving the children behind without their care. They displayed and expressed a great deal of sadness about the uncertainty of what will happen to their children with the fact that they depend on their families for survival.

In the same vein, Sandhu et al. (2017:378) also found that most families were hopeless about the future of the children with ID in case something negative befell them as parents. In addition, in support of these findings, the previous study of Irazabal et al. (2016:12) found that the families shared great concern about the future of the children with ID without them as caregivers.

6.3.4. The Need for Social and Community Support

The results of this study revealed the need for social support for the families living with ID. The following categories emerged from this theme: nuclear family; extended family; community structural support; the need for support resources and FQoL. Findler, (2014:35) defines social support as an interpersonal transaction of emotional and instrumental dimension. In addition, Meral et al. (2013:234) propound that social support is a main factor in families to determine their satisfaction on FQoL. Furthermore, Beighton and Wills, (2016:634) view social support as resources perceived from others in social networks to provide interpersonal relationships.

The study by Cohen (2013:72) corroborates the view that social support was a useful tool to enhance self-efficacy and empowerment in families caring for children with ID. However, many parents prefer peer support networks to assist them with guidance to be able to understand the condition of their children (Douglas et al., 2017:2740). In addition, Cohen, (2013:72) opine that social support enhances advocacy effort and self-efficacy for the families who care for the children with ID. Moreover, awareness of social support outside the families enhance empowerment of the families to be able to raise the children with ID (Fujioka, Wakimizu, Tanaka, Ohto, Ieshima, Yonehama & Kamibeppu, 2015:1739).

6.3.4.1. Nuclear family

As a factor of social support, the nuclear family’s sustainability depends on factors such as family cohesion or dysfunction, absent fathers, the different roles of family members and the effects of distance parenting.

6.3.4.1.1. Family cohesion

Family cohesion refers to the level in which the family members connect or separate determining the relationships among them (Findler, 2014:34). Congruent to this study finding, Bezuidenhout (2017:4) posits that family cohesion exhibits the feeling of closeness among family members. The current study findings revealed that most families were not functioning as a unit to support each other. Some family members affirmed the absent of others, especially fathers, and inactive involvement to support the child with ID as one of their own. Mothers raised a concern that most of the activities for the care of the children rested on their shoulders.

According to Manor-Binyamini (2016:104), family cohesion reflects the degree of emotional proximity among family members including collectivist qualities, mutual concern and reciprocity while providing a sense of belonging to all its members, which enhances direction in life.

Cohen (2013:73) stresses the concept of attitudinal familyism that highlights family closeness, obligation to assist each other and willing to good relationships to ensure the well-being of the entire family. However, these concepts support the notion that family becomes before the interest of the individual.

6.3.4.1.2. Family dysfunctionality

The White Paper on Families in South Africa posit that a dysfunctional family manifests conflict, misbehaviour, abuse or neglect of family members (DOSD, 2013:3). This study is in congruence with the previous study of Rani et al. (2018:36) which identified the contributory factors of family dysfunction as poor adaptability, poor partnership, lack of growth, lack of affection, and poor problem solving. The study findings have shown tension in some families. Some of the mothers have reported poor relationship with their partners, the study further revealed dysfunctional families. Townsend and Morgan (2018:106) contend that functional families nurture and support their members and provide stability in a rapidly changing world irrespective of their problems and differences.

The tension lead to some of the parents feeling guilty and depressed of bearing and bringing the child with ID to the family. Similarly, Townsend and Morgan, (2018:207) state the evidence of dysfunctional family as anger, guilt, depression, and despair among the family members. However, a normal family is the one that is functional in which interaction of family members and coping patterns indicate a healthy family (Keltner & Steele, 2019:106).

6.3.4.1.3. The absent fathers

Absent fathers in the lives of ID children, become live a huge void to these children who, lived with their mothers most of their time, and they never experienced father figure in their lives. The study findings also revealed fathers in separation with the mothers were not in contact with their children. In some families where parents were staying together, some fathers were inactively involved in the care of the children with ID as some reported to be busy at work, therefore, reducing interaction with the child. The observation of the researcher during the interviews has shown that some mothers were not concerned about the absence of fathers in the lives of the children with ID, especially older women.

The study conducted by Freeks (2017:102) in South Africa concurs with the current study findings by revealing that absent fathers have a detrimental impact of denying the children the opportunity of having father figures. In support of the findings of this study, Wilder and Granlund (2015:142) found that the birth of children with ID leads to fathers being dissociated from their families and in some cases fathers deny paternity of the child. However, Zuurmond, Nyapera, Mwenda, Kisia, Rono and Palmer (2016:7) support these study findings by revealing that in Kenya, more than half of families reported absent fathers. Boström and Broberg, (2014:819) posit that fathers need support to bring them closer to their children with ID, which enhances father-child relationship. Hence, this could promote the development of the children, as both parents will be playing their roles as expected. Furthermore, the involvement of fathers in childrearing was observed to have increase the mothers' quality of life (Nishigaki, Yoneyama, Ishii & Kamibeppu, 2016:687).

The previous study conducted by Cohen et al. (2016:305) in support of these findings, demonstrate the important role played by fathers in rearing the children with ID regarding management of their behavioural problems. The study findings of Kumar and Joshi (2015:1098), argue that the problem behaviour of children with ID caused stress to fathers, which makes it difficult for them to fulfil their parenting roles. The study of Makofane (2015:37) opines that children growing only under maternal support miss the opportunity to know the history of paternal families.

6.3.4.1.4. The roles of family members

The study findings have shown that some family members do not participate actively in the care of the children with ID and most of the roles were the responsibilities of the mothers. However, some mothers were not involving other family members to be part of the children's caregivers.

The findings of the study of Gilson et al. (2017:348) concur that families play advocacy role to ensure that the child with ID remain well informed about independent living, education, employment and community experiences. However, the families found to be the primary caregivers who further plays a vital role to ensure and maintain that children with ID live successfully in their home environment (Cagran, Schmidt & Brown, 2011:1169).

6.3.4.1.5. Distance parenting

The study findings have revealed that some of the parents including both mothers and fathers were staying away from their children. They sometimes visit home only during month-end. In one family, the mother who comes home every weekend leaves the children under the care of the grandmother who is not living with them in the same household. The distance results in insufficient interaction with the children. The findings of this study with those of Jeong et al. (2018:9) indicated that the living arrangements of working far prevent fathers from being with their children. In the same vein, the findings of the study of Makofane (2015:38) concurs that some parents only provide financial support to their children named as '*distance breadwinners'*.

6.3.4.2. Extended family

For its survival, the extended family needs the firm support of the in-laws, friends and relatives, grandparents and father figures.

6.3.4.2.1. Support from the in-laws

The White Paper on Families in South Africa defines an extended family as a multigenerational family that may or may not live in the same house (DoSD, 2013:3). The families reported to have less contact and poor relationship with the in-laws. The report showed that the caregiving circulated among nuclear family members who were living with the child with ID. The paternal in-laws isolated the family of the child with ID and were reluctant to be available for support. The in-laws include mothers, parents, brothers and sisters of ones' husband or wife. In most cases, they form part of close family members, especially in families where children are involved. Participants expressed that even those who resided in the same villages with the families were isolating the family.

Ng and Rhodes (2018:151), concur with the findings of this study that a breached relationship between the families and extended families resulted in isolation of the families. Some families reported that the in-laws were blaming the mothers for the cause of the birth of the child with ID in their families.

6.3.4.2.2. Support from friends and relatives

The families reported poor support from relatives and friends who were not able to interact actively with them. Some reported that they do not have enough time to interact with friends and relatives owing to the fact that most of their activities revolves around the care of the children with ID. However, Duran and Ergün, (2017:394) support these study findings indicating that parents who isolate themselves may be owing to disapproval and stigmatisation by their friends and some family members as well as little information about ID.

It is noteworthy that the family needs emotional support from peers, relatives and friends as informal support is crucial for every family to survive and improve their (FQoL) and some take high initiative to seek for that support (Samuel et al., 2012:113). Some families were staying with grandparents in their households who were involved in the care of the children with ID. Findler (2014:44) supports that grandparenthood may provide critical internal support to the families to raise the grandchild with ID and further recommend that grandparents be included in family programmes to relieve stress.

6.3.4.2.3. Support from grandparents

The study revealed the active participation of some grandparents of the children with ID in supporting the families. Grandparents play a major role in providing material and emotional support to the families raising the children with ID, they also give financial support with their elderly social grant to meet the family needs. Most families survive under the care of grandparents especially the grandmothers. Some ID children's parents work far away from home and live children under the care of the grandparents.

The findings are consistent with those of the study of Findler, (2014:35) indicating that grandparents play the primary role and source of support to the families and grandchildren. However, this study further found that the grandparents of children with ID were more protective to their adult children through their difficult experiences of care.

6.3.4.2.4. Father figure support

The families raised concern on the absence of a male person as father figure to raise the children with ID. Some believed that children, especially boys, need the influence of a man to grow to develop responsibility. In some families, uncles and grandfathers were providing a father figure support to raise the children. Congruent to this finding, the study of Seepamore (2015:581) concurs that the involvement of uncles and grandfathers in the children reduce the feelings of missing father.

Furthermore, Nitsch, Faurie and Lummaa (2014:431), conducted the study in Finland and found that the relationship between the children and their maternal uncles and grandfathers benefitted the children. Similarly, the study of Makofane (2015:37), supports this finding by revealing that maternal uncles and grandfathers influenced the childhood of children growing with absent fathers. Hence, the study of Teel, Verdeli, Wickramaratne, Warner, Vousoura, Haroz and Talatiet, (2016:11) state that children growing without a father figure being present in the family experience mental functioning impairment.

6.3.4.3. Community structural support

Community structural support is a factor of neighbours, local community organisations, spiritual organisations, available ID educational facilities, as well as community awareness of ID.

6.3.4.3.1. Support from neighbours

Families reported inactive involvement of neighbours towards their support to enable them to cope with the challenges of living with the child with ID. In most cases, neighbours play major role in caring for other families who are in crisis and experiencing challenges. However, the interactions with the neighbours and other community members might contribute to the family's living conditions and the acceptance or rejection of the child with ID, families of children with ID are able to get assistance from the neighbours if the interaction is good and have positive motives. Same scenario can be applied to a negative interaction, the family might experience difficulties in the community or neighbours who will find it difficult to accept the condition of the child (Zechella & Raval, 2016:1306).

Masulani-Mwale et al. (2016:876) posit that some communities subscribe to cultural beliefs that ID is a curse to the families, which lead to families being more discriminated by their own neighbours. Nevertheless, the findings of the study of Seepamore, (2015:581) found that neighbours provide emotional support to the families by comforting them in hard times.

6.3.4.3.2. Local community organisations

It is noteworthy that community-based intervention enhances family functioning by opening the platform for the family to interact, form supportive and social relationships with other people (Mulligan et al., 2014:163). In support of these study findings, Schmidt, Krajnc and Seršen (2017:12) highlight that the support programmes for the families living with ID children are available in urban areas than in rural communities. Moreover, Taderera and Hall (2017:5) view that the religious and cultural beliefs in Africa subject the families with children with ID to social stigma and discrimination.

The study results indicate lack of intervention by community health care providers to support the families. The families feel that there is an element of discrimination amongst health care workers in their communities, who are able to visit and provide support to other families who live with other chronic conditions except for children with ID. Furthermore, the findings also showed a substantial gap between the families and the spiritual organisations which they belong. In most cases, spiritual organisations including, churches within the faith community life provide specific spiritual counselling, religious education, individualised support, and worship services to their members.

The WPRPD posits that the government does not put more effort to support and empower the families living with the children with ID and further indicates that community support services are not available (DoSD, 2016:87). The availability and access of community-based services play essential part to assist families to cope during crisis (Owen, Bowers, Heller, Hsieh & Gould, 2017:211).

6.3.4.3.3. Spiritual organisations

Women in church organisations are the ones who represent the church to provide emotional support to the surrounding communities through prayers. They also play a major role in family and marriage counselling within designated religion. The study conducted by John and Montgomery (2016:304) posits that religion and spirituality-based treatment may help to enhance family resilience to raise the child with ID. However, Sajjad (2011:77) supports the findings by stating that people who attended religious services have lower rates of depression and enjoy better health.

The study findings revealed that in some areas there was very poor spiritual support from the families' churches. The families reported that they wanted to be near to God to be able to cope with their challenges. Most families were willing to continue being regular members but the demands and responsibilities of raising children with ID limited their attendance. However, in other communities, faith-based organisations play major role to support the families in need even if they are not part of the congregation.

The findings of this study resonates with those of the study of Carter and Biggs, (2016:131) revealing that in United States of America, most people were not able to be present at churches owing to the burden of caring for the children with ID. Moreover, the study conducted in South Africa by McKenzie and McConkey, (2016:539) found that families have to fall back on religious support to be able to provide the care to their children with ID. However, the study of (Rathore & Mathur, 2015:343) posit that spirituality is used by the families of children with children with ID as a defence mechanism to deal with guilt and shame of the behaviour of the child.

The findings of this study resonate with those of Pan and Ye (2015:353) that spiritual support is crucial to guide the families of PWID as they are prone to magic and devil power owing to the social stigma associated to ID. Therefore, the study of Gallagher, et al. (2015:365) posit that spirituality offered the families a way of escaping the reality of living with the child with ID.

6.3.4.3.4. Availability of ID educational facilities

Families reported lack of access to specialised schools for the children with ID. They reported that the available schools are far from their villages and it is difficult for their children to attend as day scholars. Moreover, most children were out of school owing to insufficient educational facilities for the children with ID.

In South Africa, education is a fundamental constitutional right and is the responsibility of the government to ensure availability and accessibility of educational institutions (South Africa, 1996:12). The families stay in rural communities where each village has schools for normal development children. According to INSSSC Revised Draft, the children with ID between the age of 16 and 18 years with mild and moderate ID should be trained on pre-vocational, work training or life skills to prepare them for economic and social independence (DoSD, 2009:41). However, the ECDD encourages building on educational facilities to provide education services to accommodate children with ID to avoid separate or parallel services thus promoting acceptance of the children in communities (WHO, 2012:21).

In support of these study findings, Huus et al. (2016:868) found that children with ID were out of schools owing to factors including, lack of funds, insufficient schools, insufficient trained teachers, poor infrastructure, teaching, and learning materials, and in some cases, limited accommodation at school for children living with ID. However, the National Mental Policy Framework and Strategy indicates that the vocational training services of children with mild and moderate ID fall within the responsibilities of Department of Basic Education (DoH, 2013:10).

6.3.4.3.5. Community awareness of ID

The study findings have revealed that the neighbours of families living with the children with ID lack information and awareness of ID. The families have raised that their neighbours do not understand the behaviour of children with ID and some still believe that ID is a curse to the families. Some reported that the community members blame them for the causes of disability and continue to judge them with poor care of the children with ID.

The findings of the previous study of Akturk and Aylaz (2017:351) congruent to this study found that in Turkey the parents of the children with ID who were blamed by the community members were seeking more support that is social. However, INSSSC stresses the role of governmental departments, local government and non-profit organisation (NPO) to raise awareness on ID to respect the rights of families and children with ID (DoSD, 2009:54).

6.3.4.4. The need for support resources

In the context of this study, the need for support resources involve social networking and community-based support groups.

6.3.4.4.1. Social networking

Parenting the child with ID may be a challenging process and parents begin a difficult journey of life filled with strong emotion, difficult choices and interactions with an ongoing need to care for the child. The ECDD further stresses that the introduction of early childhood intervention programmes can build effective support networks for families especially parents of children with ID (WHO, 2012:27).

The findings of this study revealed that families were not able to have social connections and relationships with other people in the society. They reported that time did not allow them to be able to interact with other as their children with ID kept them always busy. Some of the family members shared their own experiences of accepted to remain at home and stay away from friends. Some were not able to visit public spaces avoiding being discriminated by people not understanding ID. Some reported that the siblings were not feeling free to bring their peers to their homes owing to the behaviour of the sibling with ID.

Social networks play a crucial role to provide emotional and instrumental support to enhance family resilience (Wilder & Granlund, 2014:134). Congruent to this finding, the study of Su et al. (2017:1179) found that families of children with ID who received formal and informal social networks reported to feel more support to raise their children. Moreover, Mulligan et al. (2014:162) argue for the development of community services to support and enhance the health well-being of both parents and the children with ID.

In most cases, sharing of problems with other parents of children with ID increases the family’s coping strategies to live with the child (Akturk & Aylaz, 2017:350). However, parents may feel isolated in the journey of raising their child (Kumari, 2017:361). These study findings supported by the findings of the study of Yang et al. (2016:51), found that families of children with ID prefer to stay at home rather than visiting public spaces and face discrimination.

6.3.4.4.2. Community based support groups

The findings have shown great concern raised by the families to form support groups. Families as caregivers felt isolated from families with similar needs and problems and have emphasised that belonging to a support group will enable them to cope and share experiences of living with children with ID. Furthermore, the families believed that the support group would help to fulfil their emotional needs by encouraging them to express and share their feelings and experiences with other families.

According to INSSSC revised draft, support groups are defined as voluntary, social, community networks where people come together to share common experiences and provide peer counselling (DoSD, 2009:51). King and Goldberg (2015:342) congruent to these results found that support groups play essential role in proving emotional support to the families living with children with ID. In support, the ECDD asserts that support groups can provide opportunities to the families of children with ID to share experiences, encourage each and guide one another (WHO, 2012:29).

The purpose of a support group is to prevent future potential psychological challenges by teaching the families effective ways to handle emotional stress of raising the child with ID (Townsend & Morgan, 2018:189). This is similar to the findings of the study by Schmidt et al. (2017:97), who found that parents enjoyed emotional support from other parents with children with ID. However, the WPRPD indicates the necessity to subsidise peer support empowerment programmes for the children and families with ID children. Hence, these programmes are unavailable in the communities (DoSD, 2016:99).

6.3.4.5. Family quality of life

As a factor of support systems, the family quality of life involves role disempowerment, limitations to social life, and deprivation of leisure time due to the added burden and responsibilities of caring for, and living with children with ID.

6.3.4.5.1. Role disempowerment

Some family members reported the feeling of inability to perform their role as parent to take care other children. They raised a concern that taking care of children with ID has denied them the opportunities to find employment to be able to contribute to the family needs. However, one caregiver participant even cried when indicating how difficult it is to take care of the child without receiving payment from the mother of the child. The study of Sandhu et al. (2017:377) found that it is difficult to identify whether caregiving was the result of lack of employment or not seeking other employment opportunities.

6.3.4.5.2. Social life and leisure deprivation

The dependency of the children with ID resulted in most families focused on the life of the child. However, these affected all family members including the siblings who had the responsibility to ensure that they spent more time with the ID child. The findings showed that most families, as the primary caregivers sacrificed their own well-being for the benefit of the children with ID. Most caregivers put the children with ID first before their own needs. Families regarded social life outside the family less satisfactory than they would like. Some expressed a sense of loss of own social life replaced by the care of the children with ID.

Family members lost their friends owing to isolation and lack of time to interact socially. Various studies confirmed that caring for the child with ID affects the family's social life wherein they experience social stigma and discrimination (Kaur, 2013:1464). The research findings of Schmidt, Krajnc and Seršen (2017:14) corroborate with this study that the family living with children with ID experiences greater isolation and distance from social life hence this decreases FQoL. However, the study finding of Duran and Ergün (2017:394) argues that parents of children with ID restricted their social relations caused by difficulties in coping with emotional difficulties.

Some reported channelling a large amount of time and effort into activities geared towards caring of a child with ID. Furthermore, the findings indicated less time for networking with friends, greater family isolation and distance from social activities. Some families were isolating themselves from their peers and fulfilling leisure activities because their mind was dominated by the fact that they allocated their schedule in a 'programmed manner' of taking care of the child. The study conducted by Kwok, Leung and Wong (2014:1166) found that the family experience perceived stigma resulting from the impact of caregiving. In addition, the findings of Povee, Roberts, Bourke, and Leonard (2012:969) found that parents experience loss of their own life owing to independency of the children with ID, hence, the parents of children with ID spend the longest time as carers affecting their leisure (Beighton & Wills, 2016:327). However, families of children with ID need recreation time, including watching movies and outings to relieve the stress of caregiving responsibilities (Sajjad, 2011:77).

6.3.5. The Need for Financial Support

The findings revealed that the families were experiencing financial challenges to meet extra demands of the children with ID. The financial challenges caused barriers to access health care services for the family and the child. The long distances to the services incurred extra costs, which the families were not able to afford.

In South Africa, the Department of Social Development provides monthly social grant to the children with ID to assist with the care demands. Furthermore, the health services provide free medication and treatment for chronic diseases for the children and the elderly. In most cases, the role of the father is to provide financial services to the family. Hence, in this study, some families are single parent households headed by the mothers in need of financial assistance. In concurrence with the findings of this study, Keskinova, Cicevska-Jovanova and Ajdinski (2013:186) found that the families of children with ID experienced financial difficulties that needed immediate intervention. In addition, the study of Saunders et al. (2015:41) shows that children with ID have negative impact on the financial status of the families owing to unemployment related to the caregiving responsibilities.

6.3.5.1. Financial impact for the family

The financial impact of raising children with ID translates into costs associated with ID, unemployment related to caring for the child with ID, as well as social grant as a means of financial security for the child with ID.

6.3.5.1.1. Costs associated to the child with ID

The cost of special education, medical and therapy appointments, childcare, safety and entertainment for the child have negative impact on the parents’ finance. In congruent with the results of this study, the findings of Donohue et al. (2015:405) highlight that the school fees for special school in South Africa contribute to financial burden to the families of with children with ID. Furthermore, in support of the findings of this study, the National Disability Rights Policy corroborates that persons with disabilities experience greater expenses to sustain their lives (DoSD, 2015:61).

The findings revealed that having a child with ID has a major impact on the family finances. Families incurred extra-ordinary costs related to specialised education, transport services, stimulating tools such as highlighters, color-coding books, tape recorders, or background colour, etc. and medical care expenses. The financial burden affected the function of the family. Moreover, all families echoed a concern that the social grant received monthly for the children with ID was not able to cater for the needs of the child. The findings are similar to those of the World Report on Disability indicating that persons with disabilities and their families incur additional spending towards services, which are difficult to estimate (WHO, 2011:43).

6.3.5.1.2. Unemployment related to care of the child with ID

Families with children with ID reported financial constrains owing to the point that they stopped working in order to be able to care for the needs of the children (Saunders et al., 2015:41). Moreover, the INSSS to the Children with Disabilities revised draft recommended employment of the parents of children with ID by ECD or day care centres to improve poverty in their families (DoSD, 2009:38).

The results show that most mothers were unlikely to be engaged in full time jobs owing to care for their children. Mothers who were employed before the birth of children with ID had to resign and dedicate their time taking care of children. Some mothers volunteered to work few hours at the crèches in order to be able to care for the children with ID. However, some mothers found it difficult to choose between their children and jobs and in most cases, these deprived them the opportunity to generate income to alleviate poverty in their families. However, other families were dependent on mothers who were breadwinners without employment.

Most families were dependent on the social grant for the other children to meet the needs of the entire family. Those who reported to be willing to find job raised concerns about lack of childcare facilities for their children hence the available childcare centres opened late and closed early which was not suitable for working conditions. In support of these study findings, Schmidt et al. (2017:97) posit that caring and working were incompatible resulting in mothers quitting jobs or taking half-time employment in order to meet the care demands of the child with ID. Hence, the study findings highlighted the fact that caregiving burden decreases the opportunity of mothers to be employed full time. Meanwhile, these deprive them the opportunity to generate income and contribute to the society’s economic status.

6.3.5.1.3. Disability grant for the child with ID

All the families living with children with ID, were receiving the disability grant. The South African Constitution, Bill of Rights chapter 2 mandates that the citizens who are living with disability should receive special dependency disability grant from the Department of Social Development. The families showed a desperate need for the grant to be increased to enable them to meet the demands of the children with ID and the siblings whom some also received monthly social grant. Hence, most families were female-headed households and women were breadwinners who were not able to work owing to the caring responsibility of the children with ID on a full-time basis.

The families were not using the grant for the children only but for other family needs. The previous study findings of Rabe (2017:8) found that in South Africa the families that are living in poverty share the grants to meet their basic needs. In support of this findings the Limpopo Social Development Strategic Plan for 2015-2030 indicate that a large number of populations depend on social grants (DoSD, 2013:15). The findings of Seepamore, (2015:581) support the findings indicating that the social grant of the children stretched to fulfil the needs of other members of the families

All children living with families who participated in the study were receiving dependency-care grant. All families complained that the grant is not adequate to meet the needs of the children. Congruent to these findings, Adithyan, Sivakami and John's, (2017:89) study conducted in India reports that the monetary support offered by the government to the families raising children with ID was inadequate and irregular. Furthermore, the study continued to question the monitoring mechanism of the money to reach relevant families regularly. However, in South Africa, SASSA administers the social grant, to the recipients to access the money through transfers and cash, which discrepancies were common. In support of these findings, Irazabal et al. (2016:13) posit that family members have to give up work because of always busy with the care of the children with ID.

6.3.6. The Need for Economic Infrastructural Support

The study showed that some of the families in Capricorn District are living under abject poverty. However, the South African government-built houses as part of government funded social housing project to people who cannot afford to build their own houses known as rural development programme (RDP). The government also introduced free health services for children less than six years, the elderly and pregnant mothers, free basic education, including feeding schemes for the schoolchildren who cannot afford.

The South African government introduced dependency care and grant for people with disability, old age grant and grant for children under 18 years whose parents cannot afford as a means of economic support. In support of this study, the findings of the previous study of results of Zuurmond et al. (2016:6) have shown that many families were living in extreme poverty.

Congruent to this finding, Keskinova et al. (2013:186) found that families raising children with ID, experience low socio-economic status. However, economic support enhances and facilitates human development of family members. In addition, increased economic status decreases the anxiety levels of parents living with children with ID (Akturk & Aylaz, 2017:350). Hence, the WPRPD accentuates that family economic success plays a major role in driving the strengthening of the families living with children with ID (DoSD, 2016:7).

6.3.6.1. Basic needs

To a large extent, the availability and capacity to meet the basic needs of children with ID is also a measure of fulfilling their human rights, demonstrated in this study with the availability of sanitation, housing, transport and nutritional adequacy for the children with ID.

6.3.6.1.1. Sanitation

Lack of proper sanitation facilities for the families affected the daily living of the family members who made provision to ensure that the biological needs of the children were met. However, in South Africa, sanitation is one the basic needs necessity to promote good health to all the citizens. According to Capricorn District Municipality Annual Report 2016/2017, sanitation is a hygienic way of promoting health through prevention of human contacts with waste hazards. However, municipality provides RDP level sanitation, including ventilated pit latrines (VIP), French drains and ordinary pit latrines to some of the households in rural areas with a backlog of 47 percent (Capricorn Municipality, 2017:53). This report resonates with the study findings which have shown that some families have to wait long for the toilet to be built hence they were not provided with the progress of the service delivery from the municipality leaders.

6.3.6.1.2. Housing

Lack of adequate housing was a challenge to the families who had a hope to own proper houses that would provide shelter and privacy to all family members. Parents were still sharing bedrooms with the teenagers indicating lack of privacy and dignity to family members. Challenges to the families of the children with ID, were a very long waiting lists for RDP houses which are ‘controlled’ by local councillors who, at some point distribute those houses in a corruptive manner where one has to pay a fee to get the house, which is a big challenge to the families of the children with ID. Lack of employment contributed to some families being unable build adequate housing structures to meet the needs of the family members.

The Constitution of South Africa on Bill of Rights chapter 2 stipulates that every individual has the right to access adequate housing (South Africa 1996:11). In support of these study findings, the study conducted in South Africa by Donohoe et al. (2015:405) asserts that the crowding of the home environment impedes the development of children with ID. Therefore, the study further suggests that government should provide housing to the poor families.

The WPRPD posits that children with ID living in impoverished households face multiple deprivations (DoSD, 2016:89) and further indicates that the state should provide single mothers of children with ID with housing support. However, according to Capricorn District Municipality Annual Report of 2016/2017 (Capricorn District Municipality, 2017:56), the provision of housing is a function of local municipality. According to the report on Limpopo Socio-economic Review Outlook 2018/19, report on housing backlog of 25 000 houses in Capricorn District showed in 2016, indicating that most families were not living in formal dwellings (Limpopo Department of Treasury 2019:49).

6.3.6.1.3. Transport resources for the child

Not every village had access to school and day care centres for children with ID. Families raised the concern that the available transport is very expensive, and the allocated disability grant is insufficient to cater for transport costs. Major transport services in rural areas that were indicated by the families were buses and taxis. Most families reported keeping the children with ID out of school owing to lack of transport fees, which increase yearly. However, the Department of Basic Education provides free transport services to schools for children with ID. Some families were not able to access free transport for their children to school, as the route for transport was a distance from their homes. This resulted in most children unable to attend schools and day care centres.

The findings of this study are congruent with the study of Zuurmond et al. (2016:6) indicating that in Kenya, large distances, poor road infrastructure resulted in limited transport services to persons with disabilities. Furthermore, the study is supported by Capricorn District Municipality Annual Report 2016/2017 which indicate that subsidised bus transport caters less for learner transport services. Furthermore, the report indicates that this contribute to children with ID not able to access educational facilities (Capricorn Municipality, 2017:62).

6.3.6.1.4. Nutritional needs

The families raised concern to receive food assistance from the government, which is a basic need. However, according to the Limpopo Strategic Plan for 2015-2030, the Province managed to increase the household food and nutrition security (DoSD, 2013:14). In support of the study, Zuurmond et al. (2016:7) also found that children with disabilities were malnourished and less likely to be part of feeding programmes. Furthermore, some families were struggling to provide adequate food to the children with ID. Some children with ID were reported to have increased appetite and especially those with eating disorder who would even cry if they could not get what they crave for. Other family members were complaining about the children eating every available food without sharing with other members and even going to the extent of visiting neighbours for more food.

The Constitution on Bill of Rights chapter 2 determines that every person has the right to access sufficient food and water and further posit that every child has the right to basic nutrition (South Africa, 1996:11). The country provides feeding schemes at schools to provide food with balanced diet to the children of the families who cannot afford to prevent malnutrition. Hence, the feeding scheme is only accessible to the children who attend school while most of the children with ID were reported not to attend schools. The Global Report on Status of Children with Disability stipulates that children with disability were not able to access feeding programmes due to inability to attend school and feeding themselves which expose them to malnutrition (UNICEF, 2013:24).

6.3.7. Improvement Suggestions

The families suggested the strategies that can improve and increase the effectiveness of support of the families living with children with ID to enable them to cope with the challenges of raising the child. Training of families and material resources emerged as categories for this theme.

6.3.7.1. Training of families

6.3.7.1.1. The emotional well-being of the child

The families requested training on how to handle the moods of the children with ID. They highlighted that the training will assist them to be able to deal with different emotions displayed by their children with ID. Congruent with these findings, the study of Hewitt et al. (2015:165) found that physical training of the families on behaviour of the children including aggression improved their skills to handle the child and further increased feelings of competence and increased confidence.

6.3.7.2. Provision of material resources

The families experience poor resources to maintain the standard of living of raising the child with ID. The families advocated for the provision of material resources from the government to be able to cope with the challenges of caring for the children with ID. Resources to stimulate the child and the caregiving emerged as a subcategory for this theme. However, the study of Kimura and Yamazaki (2016:53) found that standard of living especially affordability of resources, as important factor for mental health.

6.3.7.2.1. Resources to stimulate the child

The findings show that families struggle to afford to buy resources for the stimulation of the children. Some reported that it is difficult to buy stimulation resources with the little disability grant that they receive for their children with ID. The stimulation programme is a skill that assists to stimulate the child’s senses including, touch, sight, hearing, smell and taste.

The availability of material resources, including toys, charts and stationery to stimulate cognitive and motor development of the child. Therefore, Dandashi et al. (2015:1) findings corroborate with those of this study that assistive technology systems including, computer-based tools, books and toys enhance the children’s concentration to be able to learn, communicate and play effectively. Therefore, most families reported lack of funds to pay for stimulation resources. However, Uys and Middleton (2014:519) opine that increased stimulation by introducing therapeutic activities leads to increase in appropriate behaviour of the child with ID.

6.3.7.2.2. The caregiving grants

Some family members, especially mothers, reported a need for caregiver disability related financial assistance apart from child disability grant received each month for the children with ID. Despite the government providing monthly dependency care grant for the children with ID, the families reported that they should be provided with monthly stipend for caregiving considering the fact that they were forced to leave their jobs to take of their children. However, some of the families were female-headed households (FHHs) who depended on social grant of their children. The findings were supported by the White Paper on Families which corroborated that FHHs are more dependent on the social grant as source of income (DoSD, 2013:19).

Pan and Ye (2015:352) support the fact that the family is the primary caregiver in the life of children with ID and further indicates that in China, the state established programmes such as “cash-for-care” to consolidate the caring role provided by the families living with PWID.

The FPSP and provision in a global context intimates that providing cash payments to the families engenders changes in child-rearing behavioural changes, especially among mothers as caregivers (UNICEF 2015:9). Therefore, the suggestion of providing the mothers with additional grant money to meet their needs, is justified.

6.4 CONCLUSION

The study findings highlighted the vulnerability of the children and the families raising them. The support of the families remains crucial for the survival of each family. For this reason, active participation on implementation of frameworks and policies is critical to all stakeholders. Such active participation enhances the capacity for support to the families’ coping mechanisms as they strive to meet the needs of the children living with ID. Good partnership with government, NGOs, NPOs and the community are necessary for a comprehensive approach to address the challenges and ensure collaboration and coordination of support services for the affected families. The next chapter discusses the development of strategies to strengthen support systems for the families of intellectually challenged children.

CHAPTER SEVEN: SUPPORT STRATEGIES OF FAMILIES LIVING WITH CHILDREN WITH INTELLECTUAL DISABILITY

CHAPTER ONE: BACKGROUND OF THE STUDY

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- 7.1. INTRODUCTION
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CHAPTER EIGHT: CONCLUSIONS AND RECOMMENDATIONS OF THE RESEARCH STUDY

7.1. INTRODUCTION

The preceding chapter discussed the findings of the study. The present chapter focuses on the development of strategies to support families living with, and caring for children with ID. Based on the research findings, the researcher hopes to be innovative, reinforce progressive infrastructure and concretise strategies that are compliant with the existing policy and legislative architecture, as well as ratified conventions such as the Convention on the Rights of Persons with Disabilities (CRPD). Therefore, family support as the fundamental support system will be considered by paying particular attention to the following family dynamics: adequate resources to families managed by a single mother; the extended family in situations where the primary caregiver is the grandmother who has to share her social grant with the whole family; and child-headed household complexity.

The developed strategy ought to address both the formal and informal support structures, including community resources such as the church, women cooperatives, community forums, and non-governmental organisations that enhance the family's capacity to manage and care for children with ID. In this regard, the role of professionals and service providers will also be strengthened to harness the effective support practices (Vilaseca et al., 2015:33).

7.2 PURPOSE OF STRATEGIES

The purpose of developing these strategies was to provide information and guidelines by using evidence-based practices on interventions that will assist policy makers on relevant actions for improving and implementing effective support systems of the families living with intellectually challenged children (Beighton & Wills, 2017:325).

7.3 SCOPE AND OBJECTIVES OF THE STRATEGIES

7.3.1 Scope of the Strategies

The support for families raising the children with ID cuts across all socio-economic sectors and most government departments. The proposed strategies are applicable to all the departments, institutions, NGOs and community structures providing services to the families living with intellectually challenged children. Furthermore, these strategies allow the strengthening and improvement of systems and programmes that support the affected families. These strategies are also intended to enhance monitoring and evaluation of the impact of the support services provided to the families (United Nations, 2006:16). All professionals and service providers rendering support services to the families raising children with ID are target groups of these proposed strategies.

7.3.2 Objectives of The Strategies

The objectives of the strategies are to:

- Describe the support systems that would help the families to cope with challenges linked to raising the child with ID;
- Facilitate the empowerment of the professionals, service providers and volunteers, as well as support to families by assisting them in developing the effective family support programmes;
- Underline the importance of all relevant stakeholders;
- Reduce the negative evaluation and feedback of services provided to families of children with ID; and
- Enhance monitoring and evaluation of the impact of the support services provided to the families.

7.4 GUIDING PRINCIPLES

The family support strategy is informed by the following principles:

7.4.1 Fundamental Equal Rights

The families should enjoy their equal rights as human beings with dignity and fundamental freedom including participation in their communities. The human rights direct the professionals on interaction and engagement with families without discrimination and judgement (Irazabal et al., 2016:8). Furthermore, this principle guides all the stakeholders to treat the family entities with respect and involve them actively in planning and intervention of support programmes.

7.4.2 Diversity

The families remain in transition and diverse with different needs and challenges. The provision of support to the families differs according to the individual family structure, beliefs, attitudes, knowledge and the different ways of addressing their own needs and community support (Irazabal et al., 2016:8).

7.4.3 Accessibility

Accessibility to basic resources is a human right that enhances sustainable independent life to the families' capacity to raise children with ID. Accessibility to support resources including, information and skills for empowerment, will further enable them to sustain the development of their children with ID (Adithyan et al, 2017:75; Pan & Ye, 2015:352).

7.4.3.1 Self-sufficiency

Each individual person depends on the opportunity to access resources to live independently. Self-sufficiency plays a crucial part to enhance competency and meaningful participation. Support interventions that include empowerment encourage the family as the responsible custodian to meet its socio-economic life to sustain the demands and challenges of raising the child with ID (Rajan et al. 2016:707).

7.4.3.2 Community strengthening

Each family forms a crucial integral part of every community and its continued survival and existence is dependent on the functioning and wellbeing of its community. Every family’s behaviour is a microcosm of the behaviour of the community and the society it emanates from (UNICEF, 2015:7). However, the government remains the custodian to promote and facilitate active involvement and participation of the community’s ability to provide support to the families living with children who have ID.

7.5 SUPPORTIVE LEGISLATIVE AND POLICY FRAMEWORK

The achievement of the purpose and objectives of the proposed strategies meant to strengthen support for families of children with ID was based on global, national and regional conventions and goals adopted by the country. However, the following legislative and policy approaches contributed to the development of the proposed strategies.

7.5.1 Global Commitments

7.5.1.1 United Nations Convention on the Rights of the Child, (1990)

This Convention describes the issues to be considered when addressing the comprehensive childcare policies and legislation to protect the legal rights of the children.

7.5.1.2 United Nations Convention on the Rights of Persons with Disabilities, (2006)

This Convention sets out and regulates the rights of persons with disabilities including civil, political, economic, social and cultural to improve their lives.

7.5.1.3 World Health Organisation World Report on Disability (2011)

This report provides guideline on promoting the lives and of persons living with disability by improving their health and human wellbeing.

7.5.1.4 World Health Organisation Early Childhood Development and Disability (2012)

The document provides and highlights the importance of strengthening ECD of children with disabilities to ensure that they have the opportunity to develop to their fullest potential.

7.5.1.5. UNICEF Promoting the Rights of Children with Disabilities (2007)

The policy provides guidelines on the rights of the children to be included and accepted as members of the society and create a conducive environment that protects their human dignity and reducing barriers to social life.

7.5.1.6 United Nations Children's Fund Children with Disabilities Report (2013)

The report provides information globally on the rights of intellectually challenged children and barriers to their development. The report accentuates the rights of children to self-determination and right to equality.

7.5.1.7 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2015)

The Convention ensures promotion and protection of fundamental human rights of persons with disabilities to ensure full enjoyment and inherent dignity for their development.

7.5.1.8 UNICEF Family and Parenting Support Policy (2015)

The policy focused on providing guidance on support of the families through the improvement of family functioning, improving the wellbeing of the child and parental competence.

7.5.2 African Continental Commitments

7.5.2.1 African Charter on the Rights and Welfare on the Child (1990)

The Charter presented by the Organisation of African Unity (OAU), protects the rights of the individual child as a uniquely privileged individual in society who ought to grow in a safe environment that promotes the physical, mental and social development.

7.5.2.2 African Charter on Human and Peoples Rights (1986)

Article 18 of the Charter focuses on protection of the family as a natural unit that forms the basis of every society and protecting the rights of persons with disabilities including their physical and moral needs.

7.5.3 National Commitments

7.5.3.1 Legislation

The Constitution of South Africa (Act No. 108 of 1996) forms the basis of the fundamental human rights of all the citizens in the country. The Act further outlines the role of social development for the support of family programmes.

7.5.3.1.1 Mental Health Care Act (No. 17 of 2002)

The Act provides guidance on the procedures for care, treatment and rehabilitation of the children with severe and profound ID.

7.5.3.1.2 The National Health Act (No. 61 of 2003)

The regulation prescribes education and training of the health care practitioners to be able to meet the criteria for provision of community care services.

7.5.3.1.3 The Children's Act (No. 38 of 2005)

Section 11 of the Act protects the rights of the children with intellectual disability, including family care, parental care and special care for growth.

7.5.3.1.4 Nursing Act (No. 33 of 2005)

The Act provides legislative means to regulate and guide nurses on delivering competent care to communities for ensuring sustenance of their wellbeing. It further defines the professional responsibility and accountability related to the scope of practice and conduct.

7.5.3.2 Policies

7.5.3.2.1 White Paper for Social Welfare (1997)

The paper provides programmatic guidelines on how to preserve and strengthen families for their protection, survival and the development of all family members.

7.5.3.2.2 National Policy Framework for Families (2001)

The policy provides guidelines on the fundamental rights of the family on rebuilding of community relationship to enhance social integration to promote family independence.

7.5.3.2.3 Education White Paper 6 (six) on Special Needs Education: Building an Inclusive Education and Training System (2001)

The paper gives direction on addressing the educational support system of children with special needs by transforming the institutions and curriculum to meet their educational needs.

7.5.3.2.4 Mental Health Policy Framework and Strategic Plan 2013-2020

The policy gives guidance on mental health promotion, treatment and rehabilitation including the prevention of mental illness in order to address the co-morbid ID.

7.5.3.2.5 Integrated National Strategy on Support Services to Children with Disabilities (INSSSCD) (2009)

The strategy is aimed at creating an enabling and healthy environment for all the children with disabilities in order to achieve their independent functioning and be able to enjoy quality of life that ensures human dignity.

7.5.3.2.6 National Development Plan (NDP): 2030 (2012)

Among other, the plan also formulates strategies to eradicate and eliminate poverty to improve the wellbeing of persons living with disabilities.

7.5.3.2.7 Integrated School Health Policy (2012)

The policy provides guidance on assessment and screening of learners at school by primary health care nurses to exclude barriers to learning through proper referral for early diagnosis, management and treatment. The policy integrates the services of education and health care services.

7.5.3.2.8 White Paper on Families in South Africa (WPF) (2013)

The White Paper guides practitioners on family issues in order to promote positive family wellbeing that will enhance socialisation, caring, nurturing and support of its members to allow them to contribute to the development of the country.

7.5.3.2.9 The White Paper on the Rights of Persons with Disabilities (WPRPD) (2016)

The White Paper guides and provides clarity on standards to remove discrimination and enhance the development of persons with disabilities. The paper further provides a framework for government and institutions to mainstream disability during the delivery of services. In addition, the White Paper provides guidance on self-representation of persons with disabilities.

7.5.3.2.10 Policy for the Provision of Quality Education and Support for Children with Severe to Profound Intellectual Disability (2016).

The policy stresses the importance of court order guidelines to achieve proper education and support for children with SPID. Furthermore, it provides guidelines for the education system to promote and protect the legal rights of the children including those with severe and profound ID.

7.5.3.2.11 Learning Programme for Children with Severe to Profound Intellectual Disability (2016).

This policy document provides guidelines for planning and development of specific learning programmes in order to achieve the full potential of children with severe to profound intellectual disability.

7.5.3.2.12 WHO country cooperation strategy 2016-2020

The policy provides guidance on attainment and achievement of health developmental programmes of the country to ensure health for all.

7.5.3.2.13 National Guidelines for Resourcing an Inclusive Education System (2018)

The policy provides guidance to the development of integrated holistic educational approach system that strengthens support of all learners with difficulty in learning at special and ordinary schools.

7.5.3.2.14 National Health Insurance Bill 2018

The Bill is aimed at ensuring universal health coverage by providing health-financing system to ensure that all citizens receive equitable health care.

7.5.3.3 Policy instruments

7.5.3.3.1 Batho-Pele – "People First" White Paper on Transforming Public Service Delivery (1997)

The Batho-Pele policy provides policy architecture on the implementation strategy, and improves the effectiveness and efficiency of public service delivery to ensure that all citizens have optimal access to services. The policy also focuses on the principles of consultation, service standards, access, courtesy, information and openness and transparency.

7.6 SUPPORT STRATEGY FOR FAMILIES OF CHILDREN WITH ID

The development of the proposed strategies was guided by themes, categories and the sub-categories emerged from the evidence of the interviews with the families living with children with ID (De Vos et al., 2014:134). The following themes aimed at supporting families living with children with ID emerged from the study findings: family well-being strategy and intervention at policy level.

The rationale for the implementation of this guideline was to provide input to the professional organisations and NGOs to develop and improve support services being provided to the families living with intellectually challenged children. Accordingly, the study's recommended strategies for the support of families raising children with ID is principally premised on two pillars, namely: family well-being and interventions at the policymaking level.

7.6.1 Family Wellbeing Strategy

7.6.1.1 Provision of psycho-educational family intervention strategy

Uys and Middleton (2014:253) propound that the essential component to empower families is to teach them about the causes, treatment and management of ID and its impact on the family. The current study supports the need to educate the families in order to provide them with adequate knowledge, which will enable them to cope with the challenges of raising their children with ID. Psycho-educational family intervention was designed to provide information and the skills to develop both the child and the family with the aim of dealing with stress. Furthermore, psychoeducation improves the families' understanding and increases the coping abilities to deal with challenges (Marshall & Ferris 2012:111; Townsend & Morgan 2018:214).

The rationale for psycho-education is to empower the families with critical information that elevates the confidence and self-reliance in caring for children living with intellectual disability.

7.6.1.1.1 Key actions to ensure effective psycho-educational family intervention

- To conduct training and coaching to families on childcare and management of challenging behaviour of children;
- The provision of information on the support services available to the families raising children with ID;

- To increase families' understanding of the use of available support resources and healthy environment for their wellbeing and the children;
- The involvement of the families on planning for effective programmes for implementation by the professionals to meet the individual family support needs;
- Education of the families on their rights and that of their intellectually challenged children to ensure their human dignity;
- To empower families on stress management to ensure health, wellness and stable mental health status;
- Teach the families on stimulation programmes that improve intellectual development of the child;
- Provide awareness on follow-up medical care programmes for children to sustain their health and reduce parental stress;
- Teach the family on conflict management to facilitate adapting coping behaviours that reduce anger and improve relationships;
- The provision of training on parental skills to improve parent efficacy in raising the child with ID;
- Provide information on the resources available to the families for improving their daily living;
- Educate the families on employment opportunities available including, part-time jobs to improve their financial status; and
- Acknowledging and respecting families' knowledge and experiences to encourage them to solve their own problems.

7.6.1.2 Promotion of family health strategy

The findings highlighted the need for promotion of healthy family to raise the children with ID. The White Paper on Families explains a healthy family as a unit in which its members display good physical, psychological and social wellbeing and promote good interpersonal relationships in their environment (DoSD, 2013:3). Persons with intellectual disability (PWID) experience behavioural challenges and psychological illnesses, including anxiety disorders, schizophrenia and mood disorders which can cause negative impact on the health of family members (Foskett, 2014:21).

The rationale is to encourage sustenance of functional families that are self-reliant and able to provide a nurturing and safe environment for the children with ID.

7.6.1.2.1 Key actions to promote family health

- To ensure comprehensive health care services that are easily accessible within the communities around the families;
- To educate the families on how to cope with the challenges of raising intellectually challenged children by empowering them with the knowledge to adapt positively and monitor and manage stress levels, as well as make proper referrals for interventions where necessary;
- The protection of rights of the families and their children with ID to ensure human dignity and promotion of their wellbeing;
- The maintenance of functional family structures that would ensure development of children with ID;
- Establishment of family-oriented approach services to enhance the family's capacity to promote the wellness of its members;
- Identification of family needs inventory to allow proper planning for supporting the families;
- Early referral of children with behavioural problems to mental health services for early diagnosis and early intervention;
- Strengthening all types of households, such as parent adjustment, the roles and responsibilities of families in raising children with ID, and instilling confidence and self-efficacy to family members by providing early intervention counselling programmes; and
- Empowering the families on identification of own needs for intervention programmes by relevant professionals.

7.6.1.3 Fathers' involvement in childrearing strategy

There is a need for fathers to assume an active role in raising children with ID. The need for the development of policies that will promote the participation of fathers in childrearing and active involvement in the responsibility of caregiving for their intellectually challenged children. The White Paper on Families asserts that the phenomenon of absent fathers who are still alive is so common, to the extent that some fathers are still are still imbued with the belief that providing material resources to care for their children (e.g. providing basic needs such as food, clothes, school fees and transport) is adequate (DoSD, 2013:24). Hence, the most crucial aspect is for fathers to be physically present to provide love and emotional support that will increase the child's sense and feeling of belongingness. The rationale is to promote quality of life by relieving mothers and other family members from the burden of being the primary caregivers of children with ID.

7.6.1.3.1 Key actions to involve the fathers in childrearing of the children with ID

- To educate fathers about ID, and to increase the number of fathers involved in the upbringing of their intellectually challenged children;
- The development of child-father programmes to promote the bond between the fathers and their children with ID;
- Formation of peer group for fathers to support each other on the challenges of fathering and heading the families of children with ID;
- Establishment and coordination of community forums for fathers of children with disability and encourage participation to support each other; and
- Encourage fathers to recognise their values and impact of parent decision making to raise the children with ID.

7.6.1.4 Sibling involvement strategy

The study findings highlighted the involvement of siblings in creation of nurturing and safe environments for the development of the children with ID. The siblings of the children with ID participate as secondary role players in assisting parents who are primary caregivers (Jacobs & MacMahon, 2016:13). As family members, the siblings ought to display positive attitudes in the environment their other intellectually challenged sibling, which enhances family cohesion in the nuclear family. Therefore, the siblings should be willing to be part of family care, but not burdened with the care of their sibling with ID.

The rationale for sibling involvement is to ensure the support of sibling and encourage them to participate actively to provide psychological support to their sibling with ID.

7.6.1.4.1 Key actions to involve siblings in support of children with ID

- Provision of therapy and counselling sessions to the siblings to enhance adjustment and acceptance of the child with ID;
- Encouragement to attend sibling events to understand ID;
- Encourage and motivate siblings to be part of the support thus improving sibling relationship;
- Provide information on the behaviour of the child with ID to enhance protection and advocating for the rights of the child with ID;

- Establish peer group support for the siblings to express their emotions and challenges of living with the child with ID;
- Encourage parents to treat siblings equally to encourage them to form part of the support architecture, and to improve the continuous support relationship with their brother or sister with ID;
- Encourage involvement of sibling in decision making regarding the caregiving of the child with ID by the parents; and
- Indicate the clear roles of the siblings and acknowledge good work done to motivate them.

7.6.1.5 Collaboration between support practitioners and family support strategy

The study findings revealed a gap between the family support providers and the families raising the children with ID. This gap created a poor relationship between them leading to ineffective utilisation of the support services around them. As a form of a cooperative and assertive means to work together, collaboration requires parties to accept mutual responsibility. Collaboration also includes open and honest communication, mutual respect, and equality in decision-making to achieve long-term goals and benefits (Marquis & Huston, 2017:559).

The rationale for collaboration is to breach the gap between support practitioners and families raising intellectually challenged children, and to enhance good communication and effective support systems.

7.6.1.5.1 Key actions to improve collaboration actions

- The improvement of communication with families to instil trust to the support services provided to them;
- To enhance interaction by encouraging regular meetings between professionals and families to share ideas and information, as well as the expression of feelings in terms of which stress level related to the burden of caring for children is reduced;
- Closing the gap between the professionals and the families living with intellectually challenged children;
- Frequency of contact with the families for early identification of difficulties to enable early interventions and home visits for accurate assessment and information about the support needs of the families; and

- Respect of the family's diversity in order to ensure equality and promote good relations and understanding of family members' behaviour.

7.6.1.6 Strengthening of Road to Health Booklet (RtHB) and Integrated Management of Childhood Illness (IMCI) services

In South Africa, all children under the age of five years attend monitoring programme through RtHB. The main purpose of the booklet is to monitor immunisation programme and developmental growth of every child. The RtHB services form part of free primary health care services and are compulsory for every child to complete the programme. The Department of Basic Education uses the RtHB as a requirement record for every schoolchild admission to the primary school programme in order to protect all children from communicable diseases. Revision of RtHB in 2011 included screening and identification of children at risk of disability (DoSD; DWCPD & UNICEF 2012:18).

The integrated management of childhood illnesses (IMCI) provides guidance on developmental screening of all children under the age of five regarding vision and adaptive, hearing and communication and motor development. However, the IMCI programme record indicates that the child who does not achieve the required developmental milestone should be referred to the relevant services including, physiotherapists. The developmental screening of children plays a significant role to diagnose the children with ID at early age of less than five years.

The rationale for this early intervention is to ensure early diagnosis of the child and the ability to plan and provide early child-family intervention that will improve the development of the child with ID.

7.6.1.6.1 Key actions to strengthen the use of RTHC and IMCI services effectively

- Education of health practitioners on developmental screening and identification of children with ID during RtHB services;
- Education of the mothers on the importance of RtHB services to improve understanding and completion of immunisation programmes;
- Referral of children with developmental problems for further management to exclude ID early and early intervention;

- Availability and accessibility of RtHB services and enhanced use of such facilities to enable assessment and early diagnosis of ID; and
- Encourage and motivate families to complete the programme for their children.

7.6.1.7 Early detection of ID and early intervention strategy

The study findings revealed the need for early diagnosis of children with learning disabilities. Such diagnosis will promote early intervention through planning of programmes that prepare for the lifelong foundation of each individual child. The study found that the implementation of Early Childhood Development (ECD) and Early Childhood Interventions (ECI) is vital for the enhancement and development of the child with ID's potential. The WHO's Early Childhood Development Disabilities (ECDD) indicates that ECD is the prenatal development period of the child from the age of eight years. Furthermore, ECDD states that ECD is the crucial period of the developmental stages of the brain including, cognitive, social, emotional, and physical development of the child (WHO, 2012:5). Child development involves the learning of simple to complex skills through a series of milestones.

The ECDD indicates that the developmental screening of children in primary community setting during programmes including, immunisations and ECD assists in the identification of children at risk of ID and the early diagnosis and referral to appropriate institutions for further assessment and treatment (UNICEF, 2013:26). ECI refers to all the programmes designed to support children with developmental delays to improve their personal development and strengthen their families (DoSD, 2016:19). South Africa introduced Grade R early educational practices to ensure the establishment of ECD. However, some children with ID still start school at a later stage compared to their peers due to lack of ECD facilities (Foskett, 2014:16).

The rationale is to provide effective support through early detection, early intervention as well as empowerment of the family members of children with ID and to provide a nurturing environment.

7.6.1.7.1 Key actions to facilitate ECD strategy

- The establishment of ECD in school environments to facilitate assessment of children with ID;

- Early identification of children with ID for planning of early developmental programmes and to be able to promote holistic response to their development and the provision of support to their families;
- Coordination mechanisms to facilitate multisector approaches to link education, health, and social welfare services to children with ID;
- The provision of training to foundation phase teachers and child health care personnel to be able to assess and identify children with ID;
- Support of primary child-care services and crèches to facilitate ECD for early identification of ID;
- Compulsory training of child-care service providers on ECD for early assessment and referral of children with ID to improve developmental status; and
- Establishment of ECI programmes in health facilities, especially school health services to support children with ID or disabilities in order to prevent complications.

7.6.1.8 Improvement of the financial and economic status support strategy

The study acknowledges the need for government policies to address the economic status of the families of children living with ID. The families experienced lack of resources to meet the basic needs required for raising the children with ID, including sanitation, housing, nutrition and transport services. The National Development Plan (NDP) 2030 posits that progress in building inclusive society without controlling economy to reduce poverty, remains fruitless and meaningless to the democracy of the country (South Africa 2012:17).

The study findings have shown that the families incur extra costs related to unavoidable errands like transporting their children to special centres, buying special food and paying school fees for remote special schools. The ECDD stresses that intellectually challenged children and their families need social protection associated to higher costs, including medical treatment, travelling costs, care assistance hence they experience limited employment opportunities (UNICEF 2013:14).

The rationale for economic development is to ensure that decision makers develop programmes and projects that will facilitate sustenance of the families to cope with financial challenges.

7.6.1.8.1 Key actions to improve financial and economic assistance to the families

- The regulation and monitoring of the disability social grants services for the benefit of the affected families;
- Proper screening of the families in need, to help improve their economic status and ability to meet their basic needs;
- Identification of families in need of housing and sanitation services through different departments in government and other stakeholders;
- Encouraging employment of parents of children with ID to improve their economic and financial status;
- The provision of poverty alleviation programmes to improve the living conditions of the children with ID and their families; and
- The inclusion of children with ID in school feeding schemes to prevent malnutrition.

7.6.1.9. Improvement of family employment opportunities strategy

The findings of this study identified the need to create employment opportunities for the family members to contribute to the improvement of the economic status of their families. Most family members were unemployed and depended on monthly social grants provided for their children and the elderly. Some gave up and lost hope to find jobs. However, they experienced the difficulty of providing for their family's basic survival needs. The WHO (2011:236) world report on disability posits that employment, apart from being a source of income, contributes to the individual's human dignity and enhances the ability to make own choices on personal life regarding talent development and capabilities.

The rationale for improvement of family employment is to create opportunities for the families to be employable and improve their personal and social wellbeing.

7.6.1.9.1 Key actions to improve family employment opportunities strategies

- Encouraging the families to improve their educational levels to increase their job opportunities;
- Decision makers to create a special employment policy that encourage employers to prioritise for the families of children with ID to reduce poverty;
- The involvement of local government to ensure establishment of community structures, including day care centres for the children with disability, which 'frees' to family members to find jobs;
- The provision of study fee assistance for families to improve their qualifications;

- The provision of specialised job training and coaching to increase their opportunities for job requirements;
- The establishment and preparation for sheltered employment for the transition of the children with ID to adulthood; and
- Coordination of funding for small businesses especially women to fight unemployment.

7.6.1.10 Promotion of stimulation, vocational training and rehabilitation programmes strategy

The study results found the need for stimulation, vocational training and rehabilitation services to improve the development and the future of the children with ID. The lives of the children with ID are in transition into adulthood, and their adjustment should start at an early age as a continuous preparation process for the demands of the world outside of their home. The families had inadequate information on stimulation, which forms the basis of the improvement of the abilities of intellectually challenged children. However, the families were concerned about the future of their children, wishing they could be equipped with the necessary vocational skills for career opportunities.

Vocational training consists of rehabilitation programmes provided in centres, and include training on specialised technical skills to children with mild and moderate ID (WHO, 2011:245). There is also a need for imparting skills in gardening, brick laying, basic carpentry, sewing, childcare, and welding can stimulate career awareness for the children and their families.

The rationale for vocational training and rehabilitation programmes is to develop the capabilities and abilities of children with ID, including preparing them to participate meaningfully in their adulthood.

7.6.1.10.1 Key actions to improve stimulation, vocational training and rehabilitation programmes

- The establishment of community-based stimulation centres to provide learning opportunities to the children and to empower the families with skills;
- The training of families on stimulation programmes to promote continuous development of the children with ID;
- The use of assistive technology systems to help the children to learn, play and communicate. The provision of assistive technology including software and computer-

based programmes can serve as stimulation tools to improve concentration span of the intellectually challenged children, thereby enhancing their interest;

- The establishment of community-based rehabilitation (CBR) centres and vocational rehabilitation centres for career guidance and teaching employment-related skills, including attitudes towards work;
- The establishment of community based vocational rehabilitation centres to teach employment skills;
- Coordination and facilitation of peer training programmes to teach each other technical skills and encourage support; and
- Collaboration between private institutions and government to mentor and coach the children and their families on career awareness and skills.

7.6.1.11 Promotion of safe environment for the child with ID strategy

The study's findings indicate that a safe environment for the children with ID is a struggle. Lack of security and protection, including at school, day care and family space in which the children are free from discrimination, abuse and exploitation, brought emotional pain to the families - especially mothers of children with ID. Moreover, the limitations induced by their mental status and inability to protect or fight for their individual rights is a continuous call for protection by families. The family should ensure a safe environment for the physical, mental and social developmental well-being of the child, and the State should ensure that the family fulfils its responsibility (United Nations 1990:8).

Discrimination and stigma experienced by children with disabilities expose them to abuse, violence and neglect in varying degrees than their peers who are without disabilities (UNICEF, 2013:41). In South Africa, PIWD were likely to be the victims of rape and sexual assault, and some reported court cases were not thoroughly investigated owing to their vulnerability as witnesses (Foskett, 2014:10; DoSD; DCWPD; UNICEF, 2012:8).

The rationale for promotion of a safe environment is to ensure that children with ID are raised in safe surroundings without any abuse and exploitation, and able to enjoy their rights as children.

7.6.1.11.1 Key actions to ensure safety and protection of the children with ID

- Public awareness on ID to empower the community on understanding of the children with ID and remove the myth related to disability;

- Community awareness on human rights of PIDs to protect the children with ID from harm and neglect;
- Family empowerment and education to reduce child abuse and exploitation;
- Advocating for non-violence family and community environment to ensure the wellbeing of the children with ID;
- To educate families about child development and brain development resources, including breastfeeding and healthy attachment to promote responsive care of the children; and
- Improvement of safety and security investigations and court proceedings when dealing with cases of abuse of children with ID to protect their rights.

7.6.1.12 Promotion of sexual and reproductive health of the children with ID

Children with ID are vulnerable to exploitation, abuse and neglect owing to their limited ability to make informed consent related to decision-making and self-protection. The World Disability Report posits the importance of professionals to consider that children with ID are human beings with sexual development. The report further posits empowerment of the families with information to protect the children with ID (WHO 2011:26).

The rationale for promotion of sexual and reproductive health is to provide the families with information on sexual development of a child with ID to enhance protection from any form of sexual abuse and diseases and prepare the children for adulthood.

7.6.1.12.1 Key strategies to promote sexual and reproductive health of the children with ID

- Educate the families on sexual development and reproductive health of children with ID;
- Encourage the families to report any form of sexual abuse to advocate for the rights of the children who are not able to defend themselves;
- Provision of counselling services to the families and the children who experiences sexual abuse;
- Establishment of sex education to the children with mild and moderate ID to prepare them for transition into adulthood, including protection from sexually transmitted diseases;

- Educate the parents on use of contraception in children with ID to prevent pregnancies that can increases the burden of caring for grandchildren in an environment that is already difficult to cope with;
- Education of the girl child on menstruation care and dealing with premenstrual symptoms to ensure protection and enhancement of self-esteem and confidence;
- Provision of sanitary towels to the girls in schools and community services to the children whose families cannot afford to buy them; and
- Family education on hygienic on male circumcision during transmission towards adulthood.

7.6.1.13 Family-centred interventions strategy

The findings highlighted the need for support programmes centred towards the needs and challenges of the families raising children with ID. The national policy framework for families posits that family-centred interventions entail a process in which support and guidance is provided to the families after thorough assessment and planning of the implementation to enhance their development (DoSD, 2001:15).

The rationale is to provide family support that meets the family challenges and needs to enable them to raise their children with ID.

7.6.1.13.1 Key actions to ensure family-centred interventions

- The establishment of basic counselling services in the communities to open a platform to express their feelings and to reduce stress and other mental related disorders induced by the effects of raising children with ID;
- Referral of the families to the relevant services to maintain continuity of support that will benefit them effectively;
- Interactions of the families with support practitioners, other families of children with ID, neighbours and community members to raise concerns about the challenges of living with the children with ID;
- Implementation of effective follow-ups services to monitor and evaluate the support services provided to the families and further identification of problems through home visit;
- Encouragement of neighbours, extended families and relatives to provide respite care to the children with ID to relieve families from the burden of caring; and

- Family therapy to help in identifying family problems and provide early intervention to promote a healthy functional family.

7.6.2 Intervention at Policy Making Level

7.6.2.1 Political participation

The study highlighted the need for political will of politicians to support the initiatives to implement the support programmes of the families living with intellectually challenged children. WHO highlights that every government has a responsibility for the health of all the citizens in the country. However, for the implementation of the responsibility, the health in all policies (HiAP) framework for country action introduced to improve population health equity. HiAP approach reflects good governance of authorities, including legitimacy, accountability, sustainability, transparency, collaboration, and participation as the cornerstone to promote the health of the citizens (WHO 2014:3).

In South Africa, the political spheres play a crucial role in decision-making to authorise legislations and bills to protect the rights of the citizens. The European multisectoral and intersectoral action for improved health and wellbeing for all policy posits that a high-level politicians' participation is given a mandate, play key indication to political will commitment and determination (WHO 2018:18). WHO South Africa Country Cooperation Strategy 2016-2020 accentuates that the national, provincial and local government have mandated both legislative and executive authority respectively that are interdependent and interrelated to implement and promote the health of the citizens (WHO 2016:3). This requires active participation and political will of decision makers to ensure dedication in strengthening the support systems of the families.

The provincial departments have the responsibility to ensure implementation of policies that provide effective support to the families. Politicians should champion family support by providing funding for the implementation of support programmes to empower the families. Participation of the decision makers that includes, ratification of family support laws, funding of programmes implementation, provision of adequate resources, capacitation of staff, community development and involvement of civil society groups. However, the World Report on Disability concurs that people's capabilities remain dependent on the government abilities to modify their external situation (WHO 2011:13).

7.6.2.2 Intersectoral collaboration of support services strategy

The study indicates that intersectoral collaboration of the support services strategy is important for the child and the family. The effectiveness of the support system of the families, provided by the government departments is not adequate because the services are provided as isolated units without the continuity and involvement of other important necessary services. The results have shown that practitioners failed to refer the needy families to other common services that can provide support to the families of the children with ID. However, this was aggravated by the fact that the families lacked information about the services available to support them. Communication breakdown of the departments leads to lack of continued support to the affected families. Sometimes this causes duplication of the work that can weaken the support system of the families.

Intersectoral action refers to the actions undertaken to collaborate other sectors to achieve health equity outcomes. In addition, the European multisectoral and intersectoral action for improved health and well-being for all policy posits that intersectoral collaboration is implemented to improve coherence in response to health and well-being challenges across sectors in which one sector is unable to address (WHO 2018:1-9). Support of the families raising the children with ID requires intervention of commitment from relevant departments to enable them to cope with the challenges of living with intellectually challenged children. The National Development Plan 2030 indicates that the country needs leadership in all sectors to improve government performance to accelerate development of the citizens (South Africa 2012:12).

The study further found the need for coordination across the following departmental ministers to engage in collaborative planning to provide support to the families through multisectoral response:
The Department of Social Development, for providing social services;
The Department of Justice, for protecting the rights of the families and the children;
The Department of Basic Education, for providing stimulation and education services;
The Department of Human Settlement, for ensuring safe environment to the families;
The Department of Labour, for providing employment to the parents;
The Department of Rural Development, for providing housing to needy families; and
The Department of Water and Sanitation, for proving the families with safe sanitation and water.

The rationale for intersectoral collaboration is to ensure coordination of support services by the appropriate departments for continuation of family support and proper care of the child with ID.

7.6.2.2.1 Key actions to achieve intersectoral collaboration strategy

- Development of policies of clear mandate to regulate collaboration of departments and management functions to improve support of families on long-term goals;
- Development of intersectoral information systems to coordinate the support of the families with children with ID;
- Formulation of procedures and guidelines to guide practitioners of relevant department on family support processes;
- Establishment of technology to facilitate communication system between different departments;
- Facilitation of effective referral system to enhance continuity of support services;
- Establishment of support structures for persons with disability and their families in each government department and ensure community awareness of such services;
- Coordination and provision of intersectoral workshops and training on support services of the families living with children with ID;
- Use of media to educate the communities on the services available for supporting the families from all the departments to encourage utilisation of such services;
- Creation of interdepartmental relationships to work towards common goals and support each other;
- The Department of Health to coordinate intersectoral collaboration to ensure sustenance of the wellbeing of the families; and
- Open communication to facilitate relationships to promote teamwork and trust between the departments.

7.6.2.3 Improvement of legislative framework strategy

Legislation framework, laws and statutes define the scope of acceptable practices and procedures to protect the human rights (Marquis & Huston, 2017:109). The results found the need to review some of the existing legislation, guidelines and policies to be consistent with UNCRPD to address support of children with ID and their families.

The rationale is to revise and align legislative framework to enforce and close the gaps in supporting the families raising the children with ID.

7.6.2.3.1. The Mental Health Care Act (No. 17 of 2002) (MHCA)

The MHCA does not address the needs of children with mild and moderate ID. It indicates admission of the children with severe and profound ID to receive care, treatment and rehabilitation. The previous studies have shown that children with ID irrespective of the level of ID have common characteristics of behaviour problem, including aggressiveness, which requires care, treatment and rehabilitation. However, such behaviours require medications that include antipsychotics drugs to save their lives. MHCA provides guidance on institutionalised care of severe and profound ID but exclude their care and support in the community. The study recommends the MHCA to include the rights of PWID to ensure proper referral system and continuous monitoring.

The rationale for this strategy is to ensure that relevant laws, policies and regulations provide clear directives on management of both institutionalised and deinstitutionalised the children suffering from ID both institutionalised and deinstitutionalised to enable the families to cope with their challenges.

7.6.2.3.2 Key actions to be taken into accounts

- Advocating for the care, treatment and rehabilitation of all the children with mild, moderate, severe and profound ID to reduce discrimination and stigmatisation;
- Involvement of other multidisciplinary teams from other departments outside health fraternity including teachers;
- Increasing the scope of practice of practitioners to provide holistic care for children with ID;
- Protection of the specific rights of the children with ID to protect them from exploitation and abuse; and
- Establish the channels to lodge complaints on infringement of the human rights of children with ID.

7.6.2.3.4. The Children's Act (No. 38 of 2005)

This Act stipulates the rights of children with ID, including the right to parental and family care. The Act does not involve the community in the care of children with ID. The study has evidenced that children with ID were the most marginalised and at risk of exploitation and abuse by the communities around them. Some of the children were living with poverty especially those from the rural areas. The study proposes evaluation of the Act to address the role of the communities to support and protect the rights of the children and their families.

The Act stipulates consideration of the children with disabilities to participate in educational facilities. The study revealed evidence that the children with ID were not safe at special schools and were not protected from other learners. Children with ID are (by law) considered as minors and cannot make informed consent. The study provided evidence that most of the children were not under the care of their biological fathers. The rationale for this strategy is to encourage protection of the rights of the children with ID by all communities, peers, families and other institutions that are in contact with the child to sustain their wellbeing.

7.6.2.3.5 Key actions to be taken into account

- Establishment of special investigation units specialising in children with ID;
- Involvement of communities in support of children with ID and their families;
- Extending parental responsibilities with regard to special needs of children with ID;
- Involvement of educators in monitoring and reporting of children maltreatment at special schools;
- Address protection of the children at special schools and include the role of educators and other staff to protect the rights of the children; and
- Extending the responsibilities of the fathers on the special needs of children with ID including medical care costs and caregiving demands.

7.6.2.4 Sustainability of family support services strategy

The study findings revealed the need to sustain the support systems available in various institutions to ensure services to the families in need. The available family support system was found to have failed the families and ineffective to provide basic services to help the families to raise the children with ID. King III Report as cited in Muller and Bester (2017:41) refers to sustainability as a way of conducting operations that meet present needs for future generational needs through consideration of environmental and social issues. Furthermore, sustainability requires planning and implementation of support systems and service providers for effectiveness.

The rationale for sustainability of family support services is to ensure that family support system services are effective to meet the support needs of the families raising the children with ID.

7.6.2.4.1 Key actions to sustain family support services

- The establishment of effective measures to enhance staff retention to address and ensure adequate resources to provide support to the families;
- Profiling children with ID to be able to identify the family's needs for proper planning of resources;
- Initiation of supervisory visits to the support systems using the evaluation tools;
- Evaluation of availability and accessibility of the support services and resources to meet the demands of the families effectively;
- The establishment of support groups to provide social practical support to the families;
- The establishment of crisis intervention centres accessible to the families to promote family readiness;
- Improvement of available services to support the families and the children with ID;
- Provision of early-childhood development assessment services;
- Coordination of the safety of the children and involvement of safety and security services in case of violation of the children and their families' rights;
- The establishment of self-navigation system to allow the family to identify their needs and choose the beneficial services;
- Encouraging adequate utilisation of the available resources and services by the families could assist with the identification of the support needed by the families;
- Facilitation of family wellness and mental health through coordination of support services;
- The establishment of family health programmes as a component of health care services to ensure custodians of the support systems;
- Improvement of psychosocial and mental health services to improve the coping skills of the families;
- The establishment of parent-child services that are composite to take care of the family and the child's needs;
- The establishment of counselling services in the communities to improve family stability;

- Implementation of effective referral system to ensure continuous family support by multi-disciplinary team (MDT);
- Development and reviews of policies and regulations to guide the support system; and
- Revival of ineffective support systems through capacitation of the practitioners and NGOs.

7.6.2.5 Capacitation and development of practitioners' support strategy

The study findings revealed the need to capacitate and support the practitioners providing support to the families with children with ID. Capacitation is a process of involvement and development through a culture of learning (Jooste, 2017:295). Provision of knowledge and resources to the support professional and practitioners enables them to carry out the task and to achieve desired goals (Clark, 2015: 242).

The rationale for capacitation and development of practitioners' support is to improve family support services to enable the members to cope with the burden of raising the children with ID.

7.6.2.5.1 Key actions to ensure capacitation and development of support practitioners

- The assessment of skills and expertise of staff including the resources to identify the needs for development and funding;
- The recruitment of specialised support staff to provide in-service training to the staff to improve their knowledge and skills to support the families;
- The establishment of capacity building programmes to the professionals and practitioners to equip them with necessary knowledge and skills;
- Facilitation of regular communication and meeting with family support stakeholders to encourage continuous support services;
- The provision of special training of employees and teachers on communication skills to enhance collaboration with the families of children with ID;
- Training and support of crèches and primary schools' staff on early childhood development to be able to perform assessments;
- The development of services and programmes that will enhance both the child and the family capacity to handle life trajectories;
- Conduct quarterly and or bi-monthly reviews to improve implementations of support programmes;

- Coordination and support of NGOs and non-profit organisations (NPOs) proving support to the families and the professionals;
- Monitoring and evaluation of family support programmes on quarterly basis to enhance effectiveness and benefits to the recipients;
- The allocation of adequate resources to the services providing support to the families to enable effective service delivery;
- Encourage peer-to-peer learning to improve understanding of the family and provision of family support;
- Support of practitioners as key role players to provide competent services to promote the wellbeing of the family members;
- Creating a motivating environment that allows the opportunity for potential growth for all practitioners; and
- The provision of in-service training and workshops to practitioners to equip them with knowledge.

7.6.2.6 Community participation and engagement support strategy

The study findings indicate the need for the community to be involved and be part of the support system to the families living with children with ID. Raising children with ID requires inclusive communities who are intensively involved and take active part to support the families.

Community engagements are actions taken to involve communities on ongoing relationships and dialogue to enable them to participate in identifying the population needs, planning, implementation, and evaluation of the programmes to meet their needs (Clark, 2015:354). The National Policy Framework for Families asserts that every community should take the responsibility in supporting and protecting its families from harm by participating on voluntary basis (DoSD, 2001:15).

The study further proposed community-based rehabilitation (CBR) programmes to involve community members to participate actively in supporting children with ID and their families. The World Report on Disability posits that CBR programmes play crucial role to challenge and change attitudes of community members in the rural areas with low development to participate actively in the development of children with ID and their families (WHO, 2011: 6).

The rationale for community participation and engagement is to facilitate the community to be ambassadors to play active role to support the families on raising the children with ID.

7.6.2.6.1 Key actions for community engagement in family support

- The establishment of CBR centres to empower families, children with ID and communities.
- Facilitation of trained community network members within the communities to enhance family support that improves family life.
- The strengthening of the relationships between the family members and the community structures.
- Encourage active community conversation and discussions on brainstorming and challenging their own beliefs and attitudes towards ID, including strategies to assist families of children with ID to be able to cope with the challenges of raising these children.
- Community volunteer members to be encouraged and motivated by means of stipends so that they are able to identify and provide support to their families and be able to perform their volunteer duties effectively.
- Active involvement of spiritual organisations such as churches and women organisations that form family support programmes should be encouraged.
- Facilitation of social network clubs for the parents of children with ID to develop a mutual help system including, “stokvels” to be able to share and provide financial assistance to the families.
- The involvement of community leaders to help to identify the needy families for relief programmes to ensure provision of nutritional meal to those who cannot afford.

7.6.2.6.2 Key strategies to improve community development

- The establishment of educational settings that involve children with ID and their families within society.
- Identification and training of community members and volunteers to support the families through respite care services.
- Collection of community information, including knowledge, attitudes, perceptions, and beliefs about ID to identify the gaps about understanding of the persons living ID and the families.

- Education of the community using media platforms on the concepts of intellectual disability to increase public awareness and understanding.

7.6.2.6.3 Key strategies to improve community empowerment

- Strengthening of community home-based care structures and encouraging the members to support the families of children with ID.
- Identification and support of the community resources, structures and programmes to support the families raising the children ID.
- Strengthening the community services on safe child-care including centres for shelter, day-care and babysitting.
- Encouragement of community members, including neighbours to provide respite care to relieve stress from the families from their caregiving burdens.
- The establishment of community based parental support to encourage parents to support each other on raising the children with ID.
- Formulation of small groups of mothers for the children with ID in the special schools and day care centres to share experiences.
- Encourage, coordinate formation of community support groups, and facilitate their existence to support the families.

7.6.2.7 Peer groups and relatives' involvement strategy

Extended families, peer groups, neighbours and relatives play major to provide informal support to the families raising children with ID. The study found that the need for this informal support is crucial because it is always at the vicinity and level of the families. Furthermore, the involvement of the family support practitioners to provide effective support through respite care, the expression of the family's feelings and the provision of the support material to the families of children with ID requires facilitation to enhance effectiveness.

Supportive social relationship of peers, extended families, neighbours, relatives, and friends of the family provide the family with the opportunity to information, and reduce the effects of psychological stress related to caregiving of the intellectually challenged children (Walker, Crawford & Leonard, 2014:243).

The rationale for peer group and relatives’ involvement is to improve involvement of peer groups, neighbours and relatives in informal support of the families raising the children with ID to be able to cope with the challenges.

7.6.2.7.1 Key actions to strengthen peer groups, neighbourhood and relatives support

- The strengthening of family friends, neighbours and relatives to improve and encourage support to the families.
- Education on respite care to relieve the families and give them short break on the care of intellectually challenged children.
- Facilitation of family neighbours, peers and relatives to become members mentors to guide the families in order to improve child-care competencies.
- Encouraging meetings, formation of social clubs and social events to improve relationships and social interaction with the family to enhance acceptance and understanding of impact of living with intellectually challenged children.
- Empowerment and acknowledgement to encourage continuation of support to the families without payback expectation.

7.6.2.8 Spirituality involvement strategy

The study findings provided clear evidence for spirituality involvement to support the families of children with ID. Spirituality refers to a search for meaning and purpose in life through nature, or belief in a higher power (Kneisl & Trigoboff, 2013:42). Spirituality plays a crucial role to help families with children with ID to cope with the stresses related to the care (Gallagher et al., 2015:359). Spiritual organisations take a lead in influencing the beliefs and values of community members. The engagement of spiritual leaders, both religious and traditional healers who yield much influencing role to the community members by educating them and utilise them as champions to support the families of children with ID. Spirituality and cultural beliefs are important to strengthen positive morale of community members.

The rationale for implementation of this strategy is to engage the spiritual leaders to be at the forefront to involve men and the community to take part in the support of the families of the children with ID.

7.6.2.8.1 Key actions to involve spiritual leaders to support the families

- Advocating against the myths and witchcraft or curses and revenge for sins by God, are perceived to be contributing factors regarding the child being diagnosed as having ID.
- Encouragement and support of the families of children with ID to seek medical attention for the treatment of psychological and mental health problems and early interventions.
- To organise community talks where guest speakers such as health practitioners, social development agencies, NGOs and NPOs are invited to give talks about ID and support to families and educate the community and make them aware of children with ID as well as their support needs.
- Encouraging and facilitating group discussion sessions with men, to make them aware that their involvement is indispensable in the care of children with ID.
- Coordination of community interactions with the families of children with ID to reduce stigmatisations and discriminations.

7.6.2.9 Prevention of prevalence of intellectual disability strategy

There is insufficient statistical information on the prevalence of children with ID and their families. There is overreliance on the reports of Statistics South Africa undertaken mainly during the annual censuses. The Department of Social Development keep statistical information for disability but not specific information according to type of disability. In South Africa, the incidence of ID was related to the impact of malnutrition, lack of access to subsequent health care, substandard education and poor prenatal care (Foskett, 2014:4).

The rationale for the above strategy is to encourage the relevant departments to provide services for children with ID to establish statistical information that will enable planning and provision of adequate resources to support their families.

7.6.2.9.1 Key actions to reduce the prevalence of intellectual disability

- Facilitation of public campaigns to encourage changing of negative attitudes and beliefs towards ID to improve acceptance.
- Awareness of the public on environmental causes of ID including low birth weight, brain injuries and toxic substances.

- Access to health care services to prevent complications that contribute to the causes of ID.
- The implementation of economic relief family economic programmes for the family and creation of job opportunities to reduce malnutrition related to poverty, which is the predisposing factor to ID.
- The establishment of genetic assessment and encouraging the family planning programme and advice to prevent unnecessary or unplanned pregnancies and to reduce the incidences of ID.
- Education of childbearing women who are at risk to make informed choices to be able to protect their unborn babies from foetal alcohol syndrome and complications of pregnancies.

7.6.2.10 Technological communication support strategy

The study findings identified the need for the use of technology to enhance the work of practitioners to plan and implement the programmes to support the families and their children with ID. The researcher observed that the introduction of technology is vital to provide network and follow-up to the support of the families.

The rationale is to provide the professionals and families of intellectually challenged children with updated information that will enable them to navigate on the services available for support.

7.6.2.10.1 Key actions to use technology to improve communication

- The development of online information products to support the families, disseminate and update the public on ID and family support.
- The establishment of database and support for children with ID and their families to enable navigation of services.
- The profile of children with ID should be accessible to all professionals and practitioners to improve facilitation and planning of support programmes.
- The establishment of social network to connect the families with peer groups and further improve social contacts.
- The establishment of information and progress on key indicators to initiate further mechanisms to improve family support.
- The sharing of research results to trace the progress on ID and families support.

- The establishment of standardised clinical guidelines that are accessible to family support professionals to provide guidance.
- Reporting platforms and recommendations to improve services and programmes on support of the families.

7.6.2.11 Initiation of respite care support strategy

Respite care is a form of support that provides some short break and relief to the family from their chores of caring for their child with ID, in or out of home, hospital and foster families (Nankervis et al., 2011:423). The evidence in this study indicates the necessity of respite care as part of support to enable the families to cope with the challenges of raising children with ID. The rationale for initiation of respite care support is to provide the family with a resting period from the burden of caring and promote interaction of the child with people outside the family.

7.6.2.11.1 Key strategies to initiate respite care support strategy

- Education of the community on respite care to instil understanding to relief the families caring for children with ID.
- Encourage relatives, friends and neighbours to assist the families by providing out of home respite care over the weekends or holidays. This will change the environment of the child and give the family members time for self-care.
- Encourage and facilitate the communities to open respite care centres for the children with developmental disabilities. This will increase the opportunities for the family to re-energise and recuperate.
- Encourage families to move the sibling out of home during school holidays to provide them with the opportunity of being in a different environment away from the caregiving environment.
- Involve community volunteers and community health care workers to provide respite care to the families to improve family functioning.
- The establishment of government facilities to provide respite care on short period and to be able to empower health care providers on the care of the children with ID.
- Active involvement of NGOs to provide respite care to promote the wellbeing of family members.
- Funding of NGOs and provision of stipends to volunteers to encourage and motivate them to continue to provide respite care.

7.6.2.12 Integration of family support in primary health care (PHC) services strategy

The study findings identified the need for integration of support programmes to meet the specific needs of the families raising the children with ID in PHC services. The WHO International Conference on Primary Health Care refers to primary health care as a comprehensive care, including promotive, preventive, curative and rehabilitative services provided to the families and communities through their full participation to maintain the ethos of self-reliance and self-determination (WHO 1978:2).

The WHO’s (2008:3) integrated health services posit integration of services as a way of achieving continuity of care on lifelong and coordinated provision of care through joint visits for separate interventions for the user. This health services approach further promotes integration to prevent fragmentation of services (WHO 2008:3). Integration of departments for common goal services initiation benefit the community, including school health programmes regulated according to the school health policy.

The rationale for family PHC support services is to initiate implementation of support services close to the families in the community to provide early intervention and referrals that will assist them to cope with the challenges of raising the children with ID.

7.6.2.12.1 Key strategies to integrate family support into PHC services.

- The formulation of policies and regulations to provide directions on family support and interventions to ensure sustainability.
- The identification of family support structures to address the gap and ensure continuation of implementation and interventions services.
- Provide clear specification of each support structure’s roles and responsibilities on the promotion and implementation of family support programmes.
- The development of standards operating procedures and guidelines for children with ID and their families.
- The screening of children with ID during immunizations programmes to be able to referral for further intervention.
- Record keeping of the children with ID to profile the children and their families for further follow up and tracing.

- The development of PHC practitioners on family support programmes to provide clear communication channels with tertiary services.
- The involvement of community structures including home based care workers to trace families with children with ID to support the families.
- Provide information and awareness of ID and care of the families of the children.
- The establishment of mobile services with support practitioners and encourage the community to utilise the service.

7.7 MONITORING OF RECOMMENDED FAMILY SUPPORT STRATEGIES

Monitoring of implementation of support programmes to ensure execution of the planned strategy plays an important part to ensure continuous delivery and sustenance of family services (UNICEF, 2007:12). Prospective evaluation of the designed support programmes and processing of evaluation during implementation, ensures quality assurance, improvement and outcome evaluation of the effect of the programme as intended to support the families (Clark, 2015: 380).

South Africa relies on other household surveys to determine the prevalence of children with disabilities. These services are exceptionally scarce and done after longer periods, which prolongs the availability of critical information relating to the types of disabilities. The scarcity is also exacerbated by different understanding of disability classification (WHO, 2012:6). This study proposes that multisectoral involvement on recording information of the intellectually challenged children, including delivery hospitals, social grants, schools, day care centres, churches and other facilities proving childcare would facilitate and improve the situation.

Monitoring and evaluation of the key indicators for children living with ID, their families of the children and the facilities available to provide family support were proposed. These indicators will assist to identify the families legible for support services. Statistical information is vital to urge the State to take the responsibility and accountability for the wellbeing of the children and their families. Statistics and consistent data collection on disability would assist with accurate information for implementation global conventions on children with disabilities (United Nations, 2008:4).

7.7.1 Key Actions to Monitor Support Systems

- The introduction of service standards and clinical practice procedures and manuals on monitoring and evaluation of family support system;
- Providing clear lines of responsibility to all practitioners and stakeholders providing family support;
- The establishment of coordination mechanisms to monitor provision of support system to the families;
- The development of the standards and procedures to implementation to support the families;
- The establishment of reporting channels on the key indicators to enable evaluation of the family support system;
- Provide guidance on clear communication channels and protocols to enhance dissemination of information on family support;
- Enforcing compliance through use of assessment tools and instruments to improve effective support system;
- Monitor accessibility standards of services through evaluation of usage capacity by the families of children with ID;
- Enhance data collection systems of ID to monitor family support indicators;
- Provide regular support visits and supervision to the practitioners to enhance motivation and commitment to provide family support;
- To conduct of service audits which will identify gaps and remove barriers for effective implementation of family support;
- The establishment of client satisfaction surveys to evaluate the support services they have received to improve acceptability;
- The development of Ombudsperson to monitor services for children with disabilities and their families; and
- The involvement of the civil society organizations (CSOs) to monitor the support systems programmes.

7.7.2 Key Indicators to Enhance Monitoring

7.7.2.1 The children living with ID

- ID prevalence among children with disability;
- Prevalence of comorbidity diseases among children with ID;

- Proportion of children living with comorbidity diseases who access treatment; and
- Proportion of children with ID living with other disabilities, including speech, hearing, blindness and physical impairments.

7.7.2.2 Families of children with ID

- The number of families headed by women only.
- The number of families and types of families raising the children.
- The number and the types of support services available in each community.
- The number of families in feeding programmes.
- The number of families utilising support services.
- The number of families interested in institutionalisation of their children.

7.7.2.3 Family support facilities

- The number of support services providing counselling services in the communities.
- The number of accredited day care centres for children with ID.
- The number of educational facilities for children with ID.
- The number of community safety services protecting the rights of the children with ID.
- The number of NGOs assisting families of children with ID.

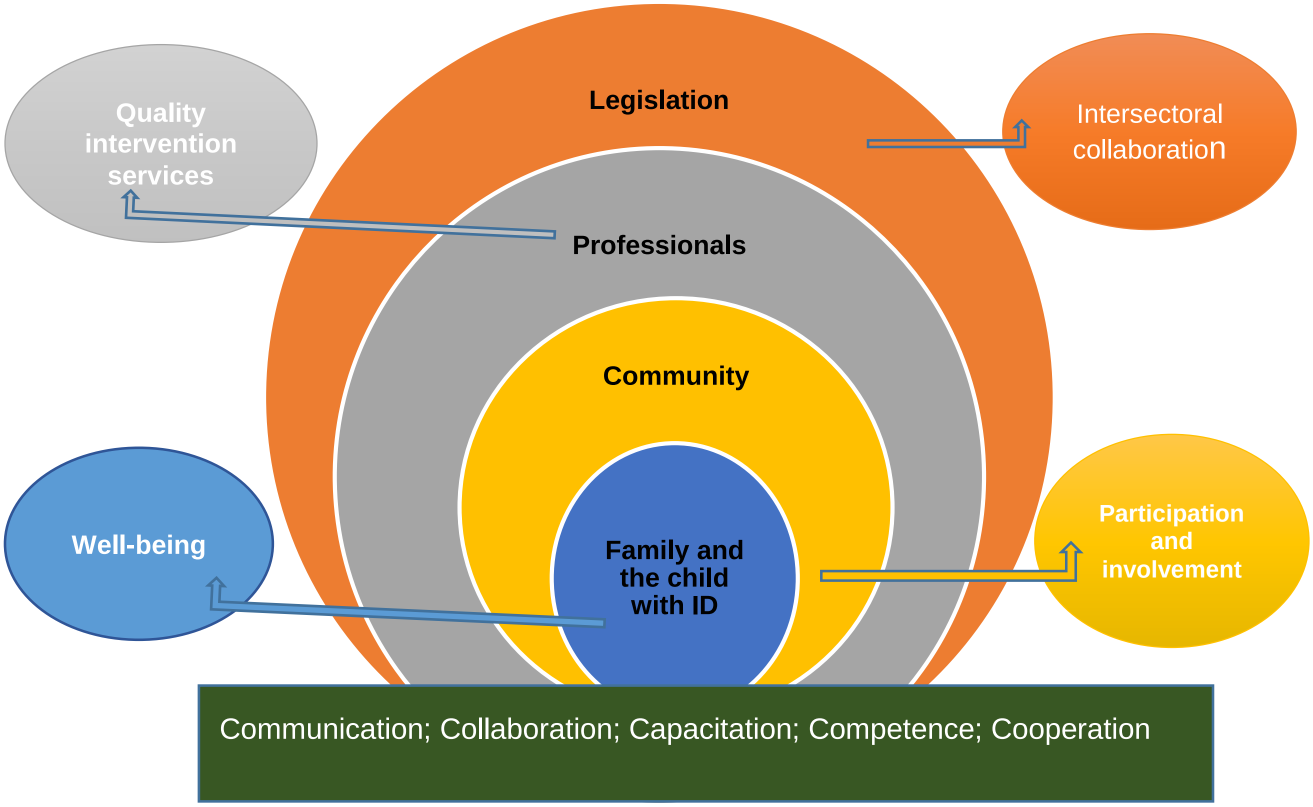

Figure 7.1: Display of summary of support strategies

The process of family support needs facilitation through development of legislation and collaboration of governmental departments to promote support of the families and their children with ID. More importantly, the capacitation of all professionals and service providers to enhance competence will ensure quality interventions to support the families (DoSD, 2009:7; Irazabal, et al., 2016:8). The involvement of communities, NGOs and civil society through good communication and cooperation will strengthen collaboration with families and enhance their wellbeing.

7.8 CONCLUSION

This chapter outlined the development of the strategies to support the families raising and living with intellectually challenged children. It is noteworthy that the decision makers play major role in providing an enabling environment for legislation and policies that promote support for families. South Africa has progressed well with the implementation programmes for other diseases. However, provision of training services and care facilities on ID is still lagging behind in other areas. This inevitably leads to marginalisation of intellectually challenged children with ID and their families, who were not receiving adequate support from the relevant support structures available.

The study has identified that active participation of relevant departments in government plays a pivotal part in applying a multisectoral approach to the support system. Recommended strategies are likely to provide a family-centred approach for the achievement of coping strategies and the wellbeing of children born with ID. However, the success and effectiveness of the proposed strategies depend on transformation, commitment and availability of resources to improve implementation of support of the families living with intellectually challenged children.

CHAPTER EIGHT: MAIN CONCLUSIONS, KEY FINDINGS, RECOMMENDATIONS AND CONTRIBUTIONS OF THE STUDY

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CHAPTER TWO: REVIEW OF LITERATURE

CHAPTER THREE: THEORETICAL FRAMEWORK

CHAPTER FOUR: RESEARCH METHODOLOGY

CHAPTER FIVE: PRESENTATION AND DESCRIPTION OF THE RESEARCH FINDINGS

CHAPTER SIX: DISCUSSION OF THE QUALITATIVE FINDINGS

CHAPTER SEVEN: SUPPORT STRAGTEGIES OF FAMILIES LIVING WITH CHILDREN WITH INTELLECTUAL DISABILITY

CHAPTER EIGHT: CONCLUSIONS AND RECOMMENDATIONS OF THE RESEARCH STUDY

- 8.1. INTRODUCTION
- 8.2. MAIN CONCLUSIONS
- 8.3. DISSEMINATION OF RECOMMENDED STRATEGIES
- 8.4. IMPLEMENTATION OF RECOMMENDED FAMILY SUPPORT STRATEGIES
- 8.5. FURTHER RESEARCH
- 8.6. CONTRIBUTIONS OF THE STUDY
- 8.7. LIMITATIONS OF THE STUDY
- 8.8. CONCLUDING REMARKS

8.1 INTRODUCTION

This study was conducted to explore and develop in-depth understanding of the experiences, challenges and coping mechanisms of the families raising and living with children with intellectual disability. An exploratory in-depth approach was utilised as the basis to obtain understanding and develop support strategies for families of these children in the Capricorn District of Limpopo Province.

The strategies were developed on the basis of the study evidence, and were expected to contribute and add value to the support systems and coping abilities of the affected families. The participants were family members directly involved in the care of the children with ID. A qualitative, explorative and descriptive research design approach was employed to collect the required information. The themes derived from this study on the lived experiences of the families were used to develop strategies to strengthen the support of the families. This chapter concludes the rest of the study with an explanation of the main conclusions, dissemination of recommended strategies, implementation of recommended family support strategies, further research, contributions and limitations of the study, as well as the researcher’s own concluding remarks.

8.2 MAIN CONCLUSIONS

The main conclusion of the study premise largely on the seven main or global themes that emerged from the evidence of the study findings. Such a theme-based perspective of the main conclusions is of absolute relevance, since ***all*** of the themes are ***directly*** linked to the core of the research purpose; that is, development of ***support strategies*** of families of children living with ID. These pertinent themes are: the need for informational support; the need for professional support; the need for psycho-emotional support; the need for social and community support; the need for financial support; the need for economic infrastructural support and improved suggestions.

On account of its qualitatively generated evidence (presented variously in Chapters 6 and 7), the study concludes that information is the key to enhancing support of the families living with children with ID. Provision of information equips and empowers families with skills and knowledge to make informed decisions for a safe environment for their children with ID (Douglas et al., 2017:2774). The provision and development of skills and knowledge to all stakeholders will ensure adequate support to the families. The competencies of the practitioners and community leaders will enable assessment and identification of family problems, as well as promote early interventions and prevention of family disorganisation.

Family empowerment is a crucial element to equip the families with knowledge of available support systems in their vicinity. Furthermore, skills on raising children with ID will improve self-efficacy and confidence. Self-efficacy of the families on the care and support of the children with ID will further instil self-confidence. Training professionals on ID and family support programmes are a means to facilitate the provision of effective family support by all stakeholders (McKenzie & McConkey, 2015:540).

The driving force for family support derives from the political will to enact bills, regulations, guidelines, and policies through legislative channels to guide the practitioners and other stakeholders, including society. Government policies play a pivotal role to set the pace at which family support strategies can be achieved. The political creates the context to facilitate the intersectoral collaboration of government departments to own and develop responsibility toward supporting the families of children with ID (Cohen, 2013:72). Participative commitments to collaborative planning of family support systems through panel of experts will facilitate implementation of support strategies and put in place effective monitoring and evaluation mechanisms to sustain the support systems.

The analytic generation and thematic development of the evidence-based themes has enabled this study to achieve its objectives by: describing the demographic profile of children living with ID in Capricorn District of Limpopo Province; exploring and describing the challenges experienced by families living with children with ID; assessing the existing support programmes and services provided to families living with ID children; and development of the support strategies to strengthen the families living with children with ID. In this regard, the study was successful, and the proposed strategies will be presented in conferences and research workshops, and made electronically available to several relevant stakeholders (De Vos et al., 2014:185; Polit & Beck, 2017: 506).

8.3 DISSEMINATION OF RECOMMENDED STRATEGIES

Dissemination of the proposed strategies to support the families living with the children with ID is directed to the ‘frontliners’ (practitioners) and stakeholders, including government departments, NGOs, Civil society, human rights organisations and other interested parties (Bogdan & Biklen, 2007:24).

It is necessary to test and confirm the implementability, appropriateness, acceptability and attainability of the proposed strategies (Gray et al., 2017:250; Maree, 2014:89). Accordingly, the proposed strategies will be presented through an intervention programme, at workshops, conferences, seminars and meetings, on research days, or contextualised in a training programme. Research articles will be published from this thesis to make the finding known to the public and research community. Furthermore, the copies of this thesis will be made available to libraries of relevant institutions and research database for access to implement change in supporting the families living with children with ID.

8.4 IMPLEMENTATION OF RECOMMENDED FAMILY SUPPORT STRATEGIES

The study recommends the following implementation by various stakeholders (Geyer, et al., 2015:112) to support the families living with children with ID.

8.4.1 Policy Development

The findings have shown the need for policy makers to establish effective monitoring and evaluation systems to strengthen the support of families raising children with ID. Moreover, the development of legislative frameworks and guidelines on support of families raising children with ID should be undertaken (Meral et al., 2013:247). Regulatory instruments and curriculum programmes should enhance and strengthen family support. The Mental Health Care Act (No. 17 of 2002 as amended) should be reviewed to address the issues of pertinent information about the care of children with ID.

8.4.2 Extended Families

The study showed evidence that family members must all be involved in the care to raise one of their own with ID. The family is the cornerstone of each individual member to survive (Moyson & Roeyers, 2012:87). Extended family members play a supportive role to each other as a unit with continuous relationship. Involvement and active participation of extended family members, including grandparents, aunt and uncles is crucial to provide support to the families.

8.4.3 Clinical Practice

The study findings suggest the need for active support programmes initiatives to support the families. The provision of continuous development, in-service training and workshops on support for the families raising children with ID should be introduced to empower the clinical practitioners with adequate knowledge. Facilitation of relevant government departments should collaborate towards supportive programmes and services to enhance sound family support. Effective referral systems should be established to ensure multi-disciplinary team approaches in the provision of support to the families (Kneisl & Trigoboff, 2013:86).

8.4.4 Community Development

The evidence from this study supports the involvement of the community to support the families of children with ID. Community awareness through campaigns can inform the public about ID. The evidence has further shown that the community lacked information on ID and unduly isolated families living with children with ID. The establishment of community support structures such as support groups, self-help groups and social clubs will empower the community on ID knowledge and information (Townsend, 2015:14). Community leaders should play active role to identity the families and facilitate support activities through volunteerism.

8.4.5 Non-Governmental Organisations (NGOs)

The study findings have shown that the available NGOs focused on the provision of basic needs to some families and centres catering for other conditions, but excluded those providing care to children with ID and their families. NGOs should consider providing resources to families for the stimulation of children in a home environment to improve and develop such children. It is also a priority to train childcare centre personnel and health care workers to equip them with knowledge and skills on ID and support of families (DBE, 2001:16).

8.4.6 The Department of Health (DoH)

The study evidence suggests that the DoH should assume leadership role to collaborate with other relevant departments in supporting affected families. Most children with ID are born in government hospitals and clinics under the care of the midwives and doctors. It is for such reasons that interdepartmental collaboration on early childhood development (ECD) and early childhood intervention (ECI) services is the key to identify the families eligible for support systems (James, 2012:23).

It is crucial to support families raising children with ID by providing school health services, immunisation of children and treatment of children with special needs, education of the parents on ID, home visits to assess family needs and proper referral to other departments. More ID public awareness campaigns should be conducted to educate the community and enhance understanding on children and persons with disability; therefore, promoting family support and reducing discrimination (UNICEF, 2007:7). The Department of Health should provide sexual and reproductive health services and information to children with ID and their families.

8.4.7 The Department of Basic Education (DBE)

The study found a need for the training of role players at Foundation Phase to ensure adequate information on ID and family support needs. The study further recommends the provision of assessment resources through ECD and ECI workshops and in-service training. Collaboration with DoH on the provision of school health services for early identification of children with ID plays a key role to identify children with ID.

The Department of Basic Education should initiate referral of children with slow progress for relevant professional services and facilitate early identification and intervention of support programmes for the affected families. This could be done through the involvement of other relevant departments to support protection of the rights of the children with ID. There is a need for monitoring and evaluation of the implementation of ECD programmes to ensure effective family support (Jansen et al. 2012:434). School-based personnel should be increased for implementation of support programmes and referral systems to learners with intellectual disability and their families.

8.4.8 The Department of Social Development (DoSD)

The Department plays a key leadership role in collaborating with other departments in the assessment and identification of the support needs of families living with children experiencing ID. Facilitation of resources to provide basic needs such as nutrition, housing and sanitation to the needy families is imperative. So is the monitoring and evaluation of community support structures and organisations (Masulani-Mwale et al., 2016:873). Accordingly, the Department should establish support programmes for children experiencing ID and their families. Moreover, the Department should coordinate support services and stakeholders involved in funding family support activities and the strengthening of families to ensure their functioning and stability. It should also provide shelter to these families and the children living with ID.

8.4.9 The Department of Human Settlements

The study findings have shown the need for the Department of Human Settlements to provide housing for families who cannot afford to provide adequate housing accommodation (DoSD, 2016:27). Housing is the mandate of the DHS, which should be involved in the provision of properly built RDP houses to families. However, the DHS has the responsibility to also hold municipalities accountable to identify the families in need of such services.

8.4.10 The Department of Justice

Most children with ID and their families face some form of discrimination and stigma from their communities. The evidence of this study has shown the challenge of exploitation and abuse of the children with ID by neighbours and other schoolchildren calling them with humiliating and derogatory names. The study findings make a clarion call for enforcement of the law by the Department of Justice to enforce protection of the human rights of the affected families and their children. The relevant stakeholders should report any form of exploitation and abuse, and the cases should be followed-up for the prosecution of offenders.

The Department must also enforce child maintenance by delinquent fathers who are not taking financial responsibility to support their children. Most families were headed by single mothers without financial assistance from the fathers of the children, resulting in poverty in the families. Some of the children were exploited by the community on duties that required payment, resulting in child labour practices such as fetching water for neighbours in return for little, or no payment.

8.4.11 The Department of Land Affairs and Rural Development

This study found the need for improvement of the economic status of families in rural areas. The study also found the need for the establishment of vegetable gardens in the communities to empower the families, especially in the villages. Accordingly, collaboration of the Department of Land Affairs and Rural Development with other departments is essential for the provision of water and land to enable families’ contributions to self-employment and the labour market (DoSD, 2013:22). This will also contribute to improvement of good nutritional status of the families and their children. Furthermore, collaboration with other departments should ensure that the families have access to housing, education and sanitation services to meet their basic needs and human rights.

8.4.12 The Department of Transport

The study findings provide evidence that most children with ID were unable to attend school and access health services owing to transport costs. Children with severe and profound disabilities were also not able to access medical treatment owing to difficulty in using public transport. There is a need for free reliable transportation of children to school. A subsidy should be provided in case the Department of Transport is not able to provide such services.

8.4.13 The Department of Labour

The study results indicated the need for the establishment of employment relief to assist mothers who are breadwinners and unemployed. The families found it difficult to sustain the family needs owing to failure to participate meaningfully in any formal economic activity, leading to the continuing vortex of poverty (Schmidt et al., 2017:99). Initiatives such as the Employee Assistant Programme (EAP) can provide relief to families and contribute to eradication of poverty.

8.4.14 Local Municipality

There is a need for local municipalities to provide sanitation to the families. The evidence of this study indicates the need for the ward councillors to identify and prioritise the families in need and update them on progress of the housing projects (DoSD, 2015:61). This encourages rapport and gains cooperation and trust with communities. Therefore, local leaders should identify families who are legible for feeding schemes that ensure good nutritional status of the children with ID.

8.4.15 The Department of Arts and Culture

The Department of Arts and Culture has a role to unite the families, communities and society as a whole through arts, culture and heritage celebrations (DoSD, 2015:61). Therefore, the Department should recognise the fact that a family is a structure that encourages socialisation of its members into the community.

8.4.16 The Department of Co-operative Governance and Traditional Affairs (COGTA)

This study found that traditional leaders played a major role in identifying the families eligible for support services from other departments, including the need for housing and feeding schemes. The Department needs to collaborate with other departments to provide the needs of the families and establishes campaigns to educate the community on ID and support of their families in collaboration with traditional healers.

8.4.17 The Department of Women, Children and People with Disabilities

The study findings revealed the need for the Department of Women and People with Disability to protect vulnerable children with ID and their families by addressing gender issues. The study also found that single women raised most of the children alone. Therefore, the Department should ensure that all women and children's rights are protected, and that they are safe and treated with respect as fellow human beings in their communities. The departments should further establish awareness projects to educate the public on equal rights of women and children, especially in an environment of a constitutionally guaranteed human rights culture.

8.4.18 The South African Social Security Agency (SASSA)

The South African Social Security Agency (SASSA) has responsibility to ensure that all eligible families receive social assistance programmes, including, grants. It improves poverty in the families that cannot survive on its own. Therefore, the identification of the families should be done through collaboration with other departments and stakeholders (AI-Kandari, 2014:120).

8.4.19 The Department of Finance

The families participating in this study lacked accessibility to basic services, including sanitation and housing. The Department of Finance is responsible for allocating and providing adequate budgets to other government departments to meet the basic needs of communities and society as a whole. In this regard, the Department should prioritise annual budget increases for SASSA allocation to families of children living with ID.

8.4.20 The Human Rights Commission (HRC)

This study found evidence of the need for the Human Rights Commission (HRC) to be involved in protecting the rights of children with ID and their families. The HRC should investigate any infringement on the rights of the families and any complaint they lodge.

However, there is also the need for the HRC to institutionalise public awareness and education on the human rights of all vulnerable people and communities (UNICEF, 2013:41).

8.4.21 The South African Police Service (SAPS)

The study found the need for the SAPS to protect the families, especially vulnerable children who are exploited and abused by their families and the community. Hence, the SAPS need to attend to family issues and violence of any form to ensure safety of children in particular, as enjoined by the Constitution (DoSD, 2016:78). Community policing will ensure safety and protection of the children from abuse in schools and in society.

8.4.22 The Civil Society Organisations (CSOs)

The study recommends the involvement of civil society organisations to monitor and evaluate the support systems provided to the families of children with ID. This will ensure that the families are able to receive the support services that ensure their care and strengthen their democracy. Involvement of civil society organisations coheres with the theme of the need for community support discussed in Chapter 5 (subsection 5.3.5).

8.5 FURTHER RESEARCH

The findings of this study provide the basis for several opportunities for future research. This study suggests that future research should be focused on the following recommendations from the findings:

- A further study that explores the experiences of professionals and practitioners in the support system for families of children living with ID;
- Specific qualitative investigation on ID professionals’ knowledge and skills concerning the support of families of children with ID;
- Further research exploring the South African context of the relationship between families of children with ID and professionals in special needs and care;
- Future studies to explore the relationship between fathers and their children with ID in the effort to improve childrearing by all family members;
- A further operational research study to evaluate the impact of the developed strategy in strengthening support for families raising and caring for children with ID; and

- Future reviews on the quality of life of families nurturing the children with ID to understand the effectiveness of support programmes aimed at strengthening them.

8.6 CONTRIBUTION OF THE STUDY

Some of the study findings were established issues also found in previous studies. However, some of the known challenges continue to exist. The study advocates for interventions targeting the challenges and problems experienced by families of intellectually challenged children. Therefore, the development of the current study's support strategies is informed by the consolidated qualitative evidence of the study. It is anticipated that the proposed support strategies can add value and strengthen the families in coping with the challenges of raising children with ID.

It is further anticipated that the proposed strategies can be used in other provinces which exhibit commonalities with those prevailing at the original research site. Ultimately, the developed strategies emanating from these study findings will contribute to the support of the families of children with ID as stated in subsections 8.6.1 to 8.6.4.

8.6.1 Development of the Strategy

Raising children with ID was a challenge among the concerned families, owing largely to the lack of support to address their needs. This study developed strategies to assist and provide input to guide improvement of support systems in strengthening and enhancing quality of life of the families living with the children with ID.

8.6.2 Policy Awareness

This study provided information on the experiences of the families living with the children with ID. The challenges faced by the families could help policy makers in various government departments providing services to PWID to consider ratification and endorsement of policies and legislation, which involve support of their families to create a healthy environment for children with ID.

8.6.3 Education and Training

The findings of this study will add value to the training of health care providers and educators as they draw and implement family support programmes. The family support programmes should focus on strengthening the families of children with ID and improve their functionalities. Positive attitudes of practitioners and support providers are instrumental for effective support systems. Inclusion of the support of families with ID in curriculum programmes will enhance family support services.

8.6.4 Body of Knowledge in Health Sciences

This study provides evidence-based information on the experiences, challenges and the needs of families raising children with ID. The study serves as a foundation for support strategy development for families living with children with ID that can be utilised to build future research.

8.7 LIMITATIONS OF THE STUDY

The study was conducted in Limpopo Province. The views regarding the support provided to families living with intellectually challenged children could not be generalised to other provinces. However, this study was supported by literature and previous studies, and the findings could be transferred to other locations displaying similar characteristics. Statistical details and information on the prevalence of children experiencing ID in Limpopo Province and Capricorn District was not available for reference and background information.

Some of the participants who initially agreed to form part of the study declined to be included on the last hour. Single mothers headed most families, most fathers migrated to cities and other provinces in pursuit of employment opportunities, which limited male interviews in the study. However, the experiences and challenges that were shared and repeated by several families contributed to the reliability of the study. Moreover, prolonged engagements during data collection benefitted the study in further exploration of the experiences of families raising the children with ID. Hence, bracketing and piloting of the study were employed to reduce these limitations. Given all these considerations, the researcher contends that the findings are scientifically valid, and that the strategies could be tested to strengthen support of the families raising children with ID. The intervention programme for developed strategies requires behaviour change of all stakeholders including the families raising the children with intellectual disability.

8.8 CONCLUDING REMARKS

The study was conducted into a two-phased process for the purpose of developing strategies to support families living with intellectually challenged children. The study provided evidence of the lived experiences and challenges of living with, and raising children with ID. The evidence further shaped a road map for the development of strategies to support the families. The combined effect of the literature reviewed (including policies and regulations) and the findings of this study, provided a foundation and guidance for the development of support strategies to for families of children with ID. In this regard, the study found it necessary for government departments, NGOs, rehabilitation centres, special schools, day-care centres, local municipalities, community leaders, faith organisations, women organisations, communities and all relevant stakeholders to participate actively in supporting families raising children with ID. The study's particular recommendation for the multisectoral approach by relevant government departments derives from the observation that an investigation on intellectually challenged children straddles several fields of study; hence, the multisectoral range of recommendations in Section 8.4. The researcher further alludes to the study's relevance and significance, given the topicality of abuse in general, and child abuse and exploitation in particular. For this reason, studies involving intellectually challenged children ought to be viewed not only as an academic exercise, but also as a concerted initiative in the fight against the continued disempowerment of children with special needs, women and indigent communities.

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UN see United Nations

UNICEF see United Nations Children's Fund

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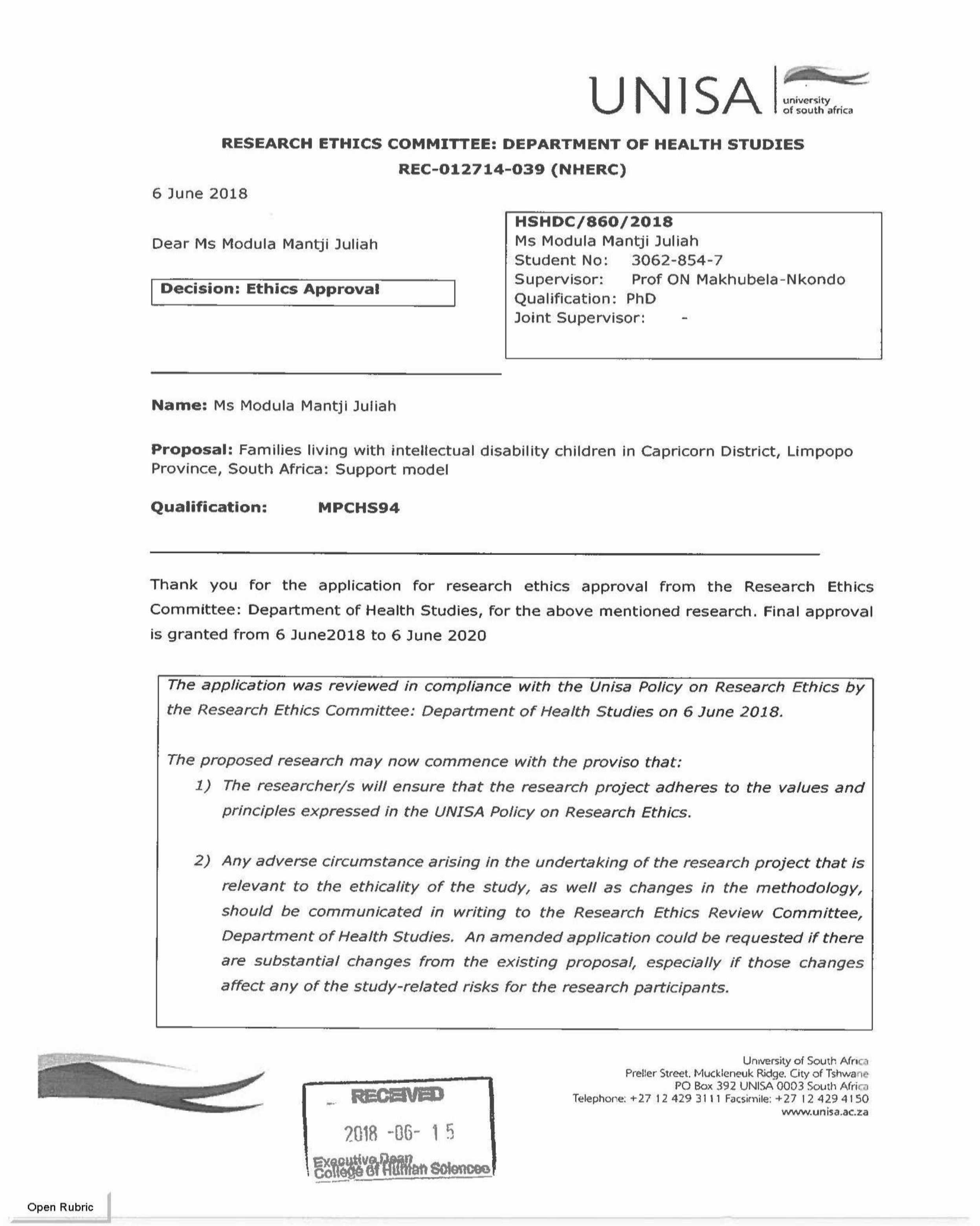
Annexure A: Ethical Clearance Ceritificate from UNISA Department of Health Studies



UNISA
university
of south africa

RESEARCH ETHICS COMMITTEE: DEPARTMENT OF HEALTH STUDIES
REC-012714-039 (NHERC)

6 June 2018

HSHDC/860/2018
Ms Modula Mantji Juliah
Student No: 3062-854-7
Supervisor: Prof ON Makhubela-Nkondo
Qualification: PhD
Joint Supervisor: -

Dear Ms Modula Mantji Juliah

Decision: Ethics Approval

Name: Ms Modula Mantji Juliah

Proposal: Families living with intellectual disability children in Capricorn District, Limpopo Province, South Africa: Support model

Qualification: **MPCHS94**

Thank you for the application for research ethics approval from the Research Ethics Committee: Department of Health Studies, for the above mentioned research. Final approval is granted from 6 June2018 to 6 June 2020

The application was reviewed in compliance with the Unisa Policy on Research Ethics by the Research Ethics Committee: Department of Health Studies on 6 June 2018.

The proposed research may now commence with the proviso that:

1) *The researcher/s will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.*

2) *Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study, as well as changes in the methodology, should be communicated in writing to the Research Ethics Review Committee, Department of Health Studies. An amended application could be requested if there are substantial changes from the existing proposal, especially if those changes affect any of the study-related risks for the research participants.*

RECEIVED
2018 -06- 15
Executive Dean
College of Human Sciences

University of South Africa
Preller Street, Muckleneuk Ridge, City of Tshwane
PO Box 392 UNISA 0003 South Africa
Telephone: +27 12 429 3111 Facsimile: +27 12 429 4150
www.unisa.ac.za

3) *The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study.*

4) *You are required to submit an annual report by 30 January of each year that the study is active. Reports should be submitted to the administrator HSREC@unisa.ac.za Should the reports not be forthcoming the ethical permission might be revoked until such time as the reports are presented*

Note:

The reference numbers [top middle and right corner of this communiqué] should be clearly indicated on all forms of communication [e.g. Webmail, E-mail messages, letters] with the intended research participants, as well as with the Research Ethics Committee: Department of Health Studies.

Kind regards,

Prof JE Maritz
CHAIRPERSON
maritje@unisa.ac.za

Prof LV Monareng
ACTING ACADEMIC CHAIRPERSON
monarlv@unisa.ac.za

Prof A Phillips
DEAN COLLEGE OF HUMAN SCIENCES

Annexure B: Request Letter to the Limpopo Provincial Department of Health

Enquiries: Modula MJ
Cell no.: 082 973 3006

P O BOX 30
FAUNA PARK
0787

The Head of Department
Department of Health
Private Bag X9302
Polokwane
0700

Sir/Madam

Request for permission to conduct a research study

I am a student at University of South Africa (Unisa) currently registered for PhD Nursing. I hereby request to conduct a research study at Capricorn health District. My research supervisor is Prof Makhubela-Nkondo, Department of Health Studies UNISA. The title of the study is: **Support strategies for families living with children with intellectual disability in Capricorn district, Limpopo Province.**

The main aim of the study is to explore and describe the support received by the families living with intellectual challenged child with special focus on formal and informal sector. The expected outcome of this study is aimed at development of strategies to improve the support systems of families living with children with intellectual disability.

The research participants will be families living with intellectually challenged children in Capricorn district. Participants will fill in consent form. Data will be collected using one-to-one semi structured interviews and focus group discussions which will be conducted until saturation of data is reached. The voice recorder will be used to capture all interview sessions and field notes will be written to capture the verbal and non-verbal data.

Attached are research proposal and the ethical clearance certificate from UNISA.

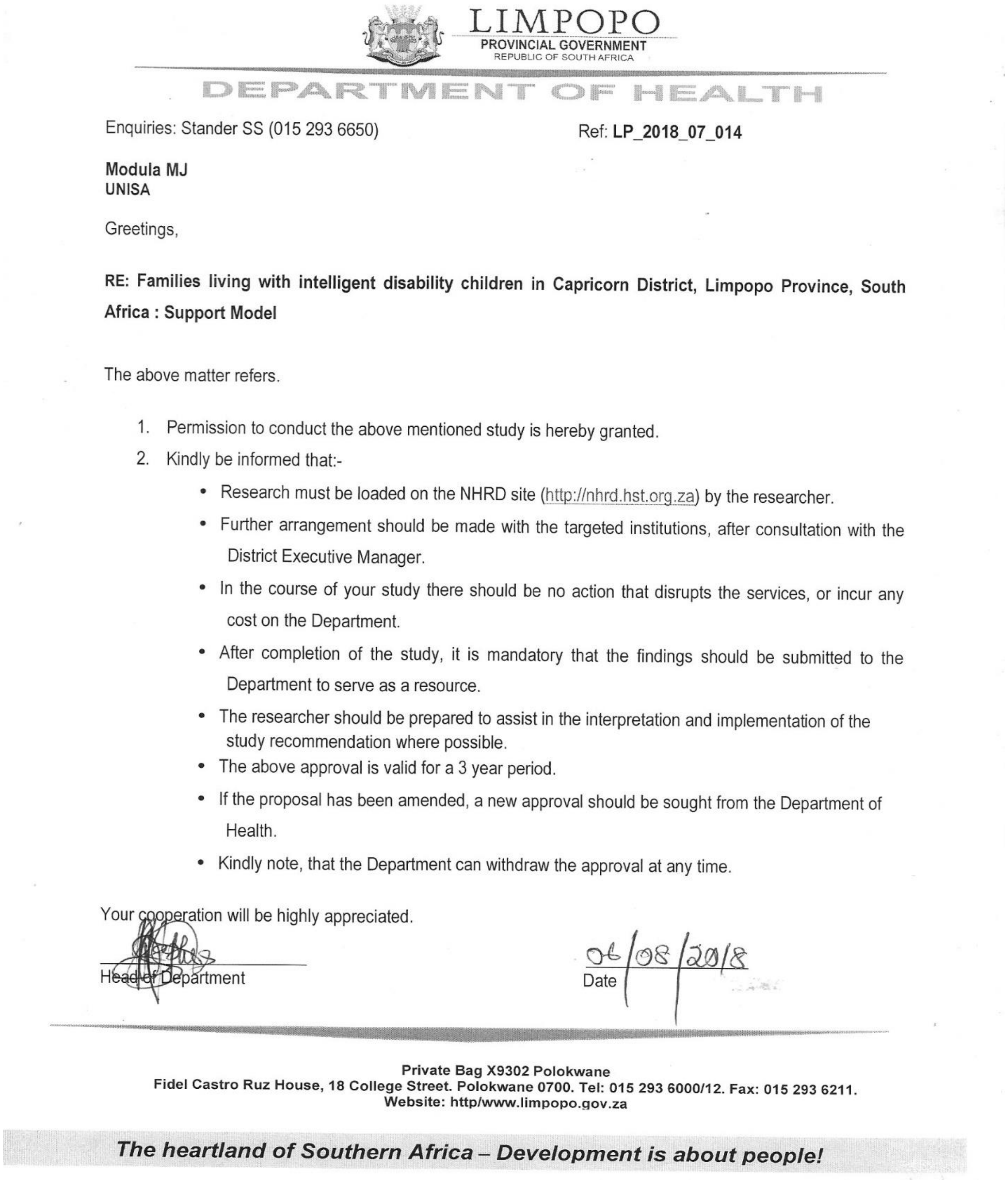
Hoping the request will be considered.

Kind Regards

16 July 2017

Modula Mantji Juliah Date

Annexure C: Ethical Clearance from the Limpopo Provincial Department of Health



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Stander SS (015 293 6650) Ref: **LP_2018_07_014**

Modula MJ
UNISA

Greetings,

RE: Families living with intelligent disability children in Capricorn District, Limpopo Province, South Africa : Support Model

The above matter refers.

1. Permission to conduct the above mentioned study is hereby granted.
2. Kindly be informed that:-
   - Research must be loaded on the NHRD site (http://nhrd.hst.org.za) by the researcher.
   - Further arrangement should be made with the targeted institutions, after consultation with the District Executive Manager.
   - In the course of your study there should be no action that disrupts the services, or incur any cost on the Department.
   - After completion of the study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
   - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
   - The above approval is valid for a 3 year period.
   - If the proposal has been amended, a new approval should be sought from the Department of Health.
   - Kindly note, that the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated.

Head of Department

06/08/2018
Date

Private Bag X9302 Polokwane
Fidel Castro Ruz House, 18 College Street. Polokwane 0700. Tel: 015 293 6000/12. Fax: 015 293 6211.
Website: http/www.limpopo.gov.za

The heartland of Southern Africa – Development is about people!

Annexure D: Request Letter to Capricorn District Health Department

Enquiries: Modula MJ
Cell no.: 082 973 3006

P O BOX 30
FAUNA PARK
0787

The Senior Manager
Capricorn Health District
Private Bag X9530
Polokwane
0700

Sir/ Madam

I hereby request permission to conduct research study at Capricorn Health District. The title of the study is: **Families living with intellectual disability children in Capricorn district, Limpopo Province: support model.**

I am a student at University of South Africa (UNISA) currently registered for PhD Nursing. My supervisor is Prof Makhubela-Nkondo, Department of Health Studies at UNISA.

Attached is the ethical clearance certificate from UNISA, approval letter from Department of Health, Limpopo Province.

The benefit of the study to the district is that the summary of the findings will be used to improve family support strategies and development of support programme for the families living with intellectually challenged child.

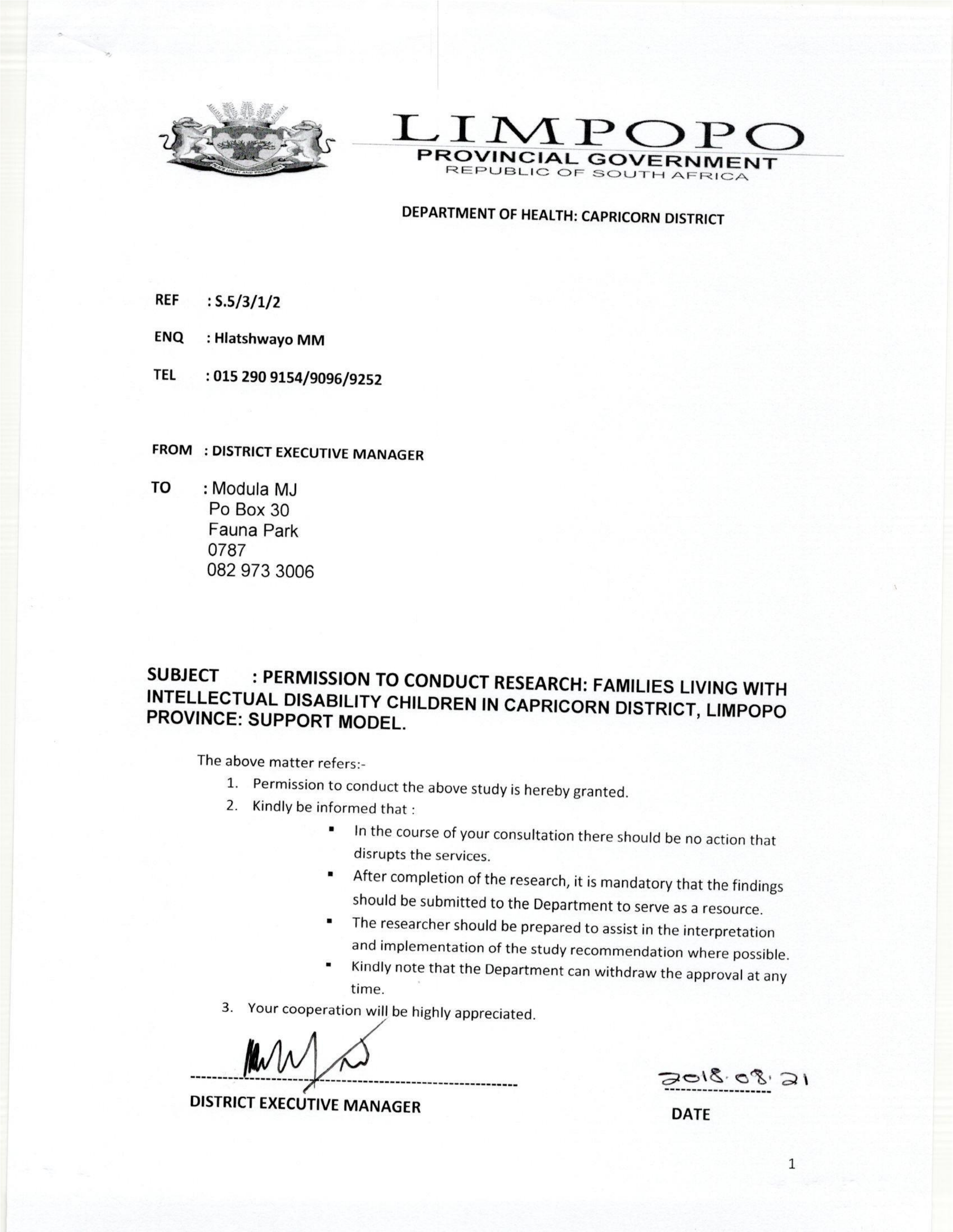
Hoping the request will be considered.

Kind Regards

16 July 2017

Modula Mantji Juliah Date

Annexure E: Ethical Clearance from Capricon District Health Department



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH: CAPRICORN DISTRICT

REF : S.5/3/1/2

ENQ : Hlatshwayo MM

TEL : 015 290 9154/9096/9252

FROM : DISTRICT EXECUTIVE MANAGER

TO : Modula MJ
Po Box 30
Fauna Park
0787
082 973 3006

SUBJECT : PERMISSION TO CONDUCT RESEARCH: FAMILIES LIVING WITH INTELLECTUAL DISABILITY CHILDREN IN CAPRICORN DISTRICT, LIMPOPO PROVINCE: SUPPORT MODEL.

The above matter refers:-

1. Permission to conduct the above study is hereby granted.
2. Kindly be informed that :
    - In the course of your consultation there should be no action that disrupts the services.
    - After completion of the research, it is mandatory that the findings should be submitted to the Department to serve as a resource.
    - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
    - Kindly note that the Department can withdraw the approval at any time.
3. Your cooperation will be highly appreciated.

DISTRICT EXECUTIVE MANAGER

2018.08.21

DATE

1

Annexure F: Informed Consent

Dear research Participant: Consent to participate in a study.

I am a PhD Nursing Science student with University of South Africa (Unisa). I am conducting a research study on the families living with intellectual disability children in Capricorn district, Limpopo Province. You are invited to participate in the study project.

The main aim of the study is to explore the support received by the families living with intellectual challenged child with special focus on formal and informal sectors. The proposed study will help the researcher to learn more about your experiences of the support systems of families living with intellectual disability child. The information obtained will result in knowledge to propose recommendations of the strategies to improve the support system of families living with intellectual disability child.

You are invited and requested to participate in individual in-depth interview, which will approximately last for 45 minutes or focus group discussions of more than two hours. You will be required to answer questions during the interview session. Interviews will be audio taped for the purpose of later transcriptions by the researcher. The proposal has received written approval from Research Ethics Committee of UNISA, Limpopo health authorities as well as Capricorn Health District management where the study will be done.

Your participation will be voluntary; there is no compensation or material benefit that will be given. All information will be treated as confidential and your anonymity is protected.

Should you wish to contact the researcher for any enquiries, questions or comments do not hesitate to contact researcher at cell no. 082 973 3006.

I…………………………………hereby voluntarily give consent to participate in the study.

Participant's signature………………………… Date……………………………………

Witness' signature ………………………. Date……………………………………

Investigator's signature …………………….. Date……………………………………

Annexure G: In-Depth Interview and Focus Group Discussion Guide for Families Living with Intellectually Challenged Child

I am Mantji Juliah Modula conducting a study that aims at exploring the support needs of families living with intellectually challenged child in Limpopo Province. The study participants include all family members living with a child diagnosed with ID. I would like to ask you few questions to explain your experiences with regard to the support of families living with a child diagnosed with intellectual disability.

The information you will share will be used to identify the support needs of families living with a child with intellectual disability and identify alternative strategies to support you as an immediate family member to the child diagnosed with ID. Your answers will be kept completely confidential and will not be shared with anyone. Anonymity is hereby guaranteed, no one will be able to identify your personal answers.

If you feel uncomfortable with any of the following questions, you do not have to answer. It is expected that the interview session will take more or less 45 minutes in individual interviews and more than two hours in focus group discussions.

SECTION A: SOCIO-DEMOGRAPHICS

Kindly provide the following information in terms of Demographics:

Information of the child

1. Age of the child in years…………………
2. Gender of the child ☐ Male ☐ Female
3. What other diagnosis has your child received? …………………………………….
4. Grade of the child ……………………………………………………………………
5. Type of the school …………………………………………………………................
6. Grant support …………………………………………………………………………
7. Is this the first child with the diagnosis? ☐ Yes ☐ No

Information of participants

8. Age ………………………….
9. Gender ………………………………..
10. Relationship to child: ☐ Mother ☐ Father ☐ Sibling ☐ Guardian ☐ Uncle ☐ Aunt

☐ Grandmother ☐Grandfather

11. Educational Qualifications ……………………………………………………….
12. Religion…………………………………………………………………………..
13. Marital status ☐ Married ☐ Divorced ☐ Separated ☐ Widowed
14. Employment status ……………………………………………………………
15. Source of income ……………………………………………………………….

SECTION B: INDIVIDUAL IN-DEPTH INTERVIEW

INFORMATION REGARDING THE CHALLENGES AND SUPPORT NEEDS

Please provide detailed information regarding the experiences of living with the children with ID and support needs you expect to receive. (Guidelines below)

1. Do you have access to relevant information or trained about care of the child with intellectual disability? **Yes/ No**

1.1 If yes please elaborate
………………………………………………………………………………………………
……………………………………………………………………………………………

2. What is your role/contribution do you offer as a family member to care for your child with ID?
..……………………………………………………………………………………………
………………………………………………………………………………………………

3. Did you receive any form of counselling? **Yes/ No**

3.1. If yes please elaborate
………………………………………………………………………………………………
……………………………………………………………………………………………

4. How do you as a whole family cope with and manage the effects of living with a child diagnosed with ID?
………………………………………………………………………………………………
………………………………………………………………………………………………

5. Explain your family professional relationships …………………………….................
………………………………………………………………………………………………

6. Are you receiving any support from relatives/ friends/ community? **Yes/ No**

6.1. Please elaborate your answer
……………………………………………………………………………………………
……………………………………………………………………………………………

7. Explain the assistance that are you receive from the health professionals in this regard?

……………………………………………………………………………………………
…………………………………………………………………………………

8. What services available to support your family to meet your challenges?
   ……………………………………………………………………………………………
   ……………………………………………………………………………………………

9. What legal rights do the family have with regard to care and support of the child?

……………………………………………………………………………………………
   ……………………………………………………………………………………………

10. In your opinion what can be done to help and support the family members to manage living with ID child effectively?

……………………………………………………………………………………………
   ……………………………………………………………………………………………

11. How does the effect of living with a family member diagnosed with ID make you feel?
    ……………………………………………………………………………………………
    ……………………………………………………………………………………………

12. What challenges do you experience as a family, resulting from living with ID child?
    ....
    ....

SECTION C: INTERVIEW GUIDE FOR FOCUS GROUP DISCUSSION

“**Describe your experiences regarding of raising child with intellectual disability”**

1. What is your understanding of the causes of intellectual disability of your child?
2. At what age was your child diagnosed with Intellectual disability?
3. Describe the behaviour of your child.
4. How do you stimulate the child at home?
5. Explain the resources available in the community to enable you to cope with the care of the child.

<u>THANK YOU FOR YOUR PARTICIPATION</u>!!!

Annexure H: Tumelelo ya go tšea karalo ya mo dinyakišišong

Motšeakarolo wa dinyakišišo: Tumelelo ya go tšea karolo ka mo dinyakišišong.

Ke moithuti wa PhD dithutong tša booki mo Unibesiting ya Afrika Borwa ye e tsebagago ka leina la Unisa. Ke dira dinyakišišo ka malapa ao a dulago le bana ba go se itekanele monaganong ka Capricorn District, Limpopo Province. O memiwa go tšea karolo ka gare ga dinyakišišo tše tša thuto.

Maikemišetšo a dinyakišišo tše ke go sekaseka le go tseba ka maemo a thekgo ya malapa ao a dulago le bana bao ba sa itekanelago monaganong gomme e lebišitše kudu go dikarolo tšeo di rulagantšwego le tša go se rulaganywe. Thuto ye e akanywago e tla thuša monyakišiši go ithuta kudu ka maitemogelo a ditirelo tša thekgo tšeo di fiwago malapa ao a godišago bana bao ba sa itekanelago monaganong. Dipoelo tša gotšwa ditshedimošong tše di tla go humanwa di tla tliša tsebo ya dikakanyo le ditšhišinyo tša maano a go kaonafatša thekgo ya malapa ao a godišago bana bao ba sa itekanelago monaganong.

O memiwa le go kgopelwa go tšea karolo go mo dipoledišanong tšeo di tseneletšego, e tla go tšea metsotso yeo e ka ba go ye masome-nne hlano goba go sehlopha sa go ahlaahla ye e ka fetago di iri tše pedi. O tla swanelwa ke go araba dipotšišo ka gare go kopano tatelano. Dipoledišano di tla gatišwa go setšeamantšu go kgontšha monyakišisi go ngwalolla ka morago. Tšhišinyo ya dinyakišišo tše tša thuto di humane tumelelo yeo e ngwadilwego go tšwa go komiti ya melao ya boitshwaro ya dinyakišišo ya Unisa, babuši ba Kgoro ya tša Maphelo Limpopo le Molaudi wa Maphelo Capricorn District.

Go tšea karolo ka go nyakišišo ye ke boithaopo; mme ga go tefo goba mokgwa o mongwe wa letseno wo o tla go fiwa. Tshedimošo e tla tšeiwa go ba ya sephiri gomme go se tsebege ga gago go tla šireletšwa. Ge go ka direga gore o be le takatso ya go ikgokaganya le monyakišiši go dilatišišo, dipotšišo goba ditshwayo, o se ke wa tšhaba go lletša monyakišiši mo nomoro ye ya sellathekeng 082 973 3006.

Nna …………………… ke fa tumelelo ya boithaopo go tšea karolo thutong ye.

Mosaeno motšea-karolo ……………………………… letšatši-kgwedi…………………….

Mosaeno wa hlatse …………………………………… letšatši-kgwedi…………………….

Mosaeno wa monyakišiši …………………………...letšatši-kgwedi……………………..

Annexure I: Individual In-Depth Interview and Focus Group Discussion Guide of Family Members Living with Intellectually Challenged Child

Ke nna Mantji Juliah Modula. Ke dira dinyakišišo tša thuto tšeo maikemišetšo a tšona e le go go nyakišiša dinyakwa tša thekgo go malapa ao a dulago le bana ba go se itekanele monaganong ka Limpopo Province.
Batšeakarolo ke malapa ohle ao a dulago le bana ba go se itekanele monaganong. Nka rata go ka go botšiša gore o hlalose ka ditiragalo tšweletšwa mabapi le thekgo ya malapa ao a dulago le bana ba go se itekanele monaganong.
Tshedimošo yeo o e abago e tla thuša go hlaola dinyakwa tša thekgo go malapa ao a dulago le bana ba go se itekanele monaganong. Dikarabo tša gago di tla tšeiwa go ba sephiri go felelela, gomme di ka se abelwe go yo mongwe. Go se tsebege ga gago go tla šireletšwa gomme ga go motho yo a ka kgonago go hlaola dikarabo tša gago.

Ge o ikwa o sa lokologa ka tše dingwe tša dipotšišo ona le maloka a go se arabe. Go letetšwe gore ka gare go kopano-tatelano ye e ka bago ka godimo goba ka fase ga metsotso e masome-nne hlano ka go motho poledišano, le go feta di iri tše pedi ka go sehlopa sa go ahlaahla.

SERIPA SA PELE: LEAGO-DIPALOPALO

Ka boikokobetšo efa tshedimošo ka dipalopalo tšeo di latelago:

Tshedimošo ka ngwana

1. Mengwaga ya ngwana …..……………………………………………………………
2. Bong bja ngwana ☐ Bonna ☐ Bosadi (laetša kgetho ya gago ka x)
3. Ke afe malwetši a mangwe ao ngwana a na go le ona ………………………….
4. Mphato sekolong ………………………………………………………………..
5. Mohuta wa sekolo ………………………………………………………………..
6. Letseno la thekgo ………………………………………………………………..
7. A ke ngwana wa mathomo wa go ba le bolwetši bjo? ☐ Ee ☐ Aowa (laetša kgetho ya gago ka x)

Tshedimošo ka motšeakarolo

8. Mengwaga ……………………

9. Bong ☐ Bonna ☐ Bosadi (laetša kgetho ya gago ka x)

10. Kamano le ngwana: ☐ Mma ☐ Papa ☐ Ngwaneno

☐ Mohlokomedi ☐ Malome ☐ Mmane ☐ Mmemoglo ☐Grandfather (laetša kgetho ya gago ka x)

11. Ditshwanelo tša thuto …………………………………………………… …………

12. Tumelo ……………………………………………………………………………..

13. Maemo a lenyalo ☐ Nyetše ☐ Hladile ☐ Kgaogane

☐ Hlokofaletšwe (laetša kgetho ya gago ka x)

14. Leemo la mošomo ……………………………………………………………..

15. Letseno la tšhelete ……………………………………………………………

SERIPA SA BOBEDI: POLEDIŠANO YEO E TSENELETŠEGO YA MOTHO KA MONG

Ka boikokobetšo efa tshedimošo yeo e tletšego mabapi le diphihlelo tša go godiša ngwana wa go se itekanele monaganong le thekgo yeo o e letetšego go e humana ya dinyakwa (Ditsamaišo tše di latelago)

1. O kgona go filhlelela tshedimošo ya maleba go ba o rutilwe ka ga hlokomelo ya ngwana wa go se itekanele monaganong? **Ee/ No (kgetha karabo ya maleba)**

1.1. Ge o dumela, ke kgopela gore o hlalose
………………………………………………………………………………………
………………………………………………………………………………………
………………………………………………………………………………………
………………………………………………………………………………………

2. O raloka karolo efe/thušo yeo o e abago bjalo ka molelapo go hlokomelo ya ngwana yo a sa itekanelago monaganong?

..………………………………………………………………………………………

…………………………………………………………………………………………

………………………………………………………………………………………

3. Go na le hlabollo yeo o e humanego? **Ee/ Aowa (Kgetha karabo ya maleba)**

3.1. Ge o dumela, hlalosa ka go tsenelela
………………………………………………………………………………………
………………………………………………………………………………………
………………………………………………………………………………………
………………………………………………………………………………………
………………………………………………………

4. Lelapa le kgona bjang go kgotlelela le go laoala ditlamorago tša go dula le ngwana wa go se itekanelo monaganong?

…………………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………
………………………………………………………………………………

5. Hlalosa kamano ya lapa le ditsibi le ditšwerere tša maphelo
   …………………………………………………………………………………………
   …………………………………………………………………………………………
   …………………………………………………………………………………………
   …………………………………………………………………………………………
6. Naa go na le thekgo yeo o e humanago go tšwa go maloko a lapa/bagwera go ba badudi ba motse? **Ee/ Aowa (Kgetha karabo ya maleba)**

   6.1. Ka boikokobetšo hlalosa
   ……………………………………………………………………………………
   ……………………………………………………………………………………
   ……………………………………………………………………………………
   ……………………………………………………………………………………
   ……………………………………………………

7. Hlalosa ka thušo yeo o e humanago go tšwa go badiredi ba tša maphelo ka seo?

   …………………………………………………………………………………………
   …………………………………………………………………………………………
   ……………………………………………………………………………………

8. Ke ditirelo di fe tšeo di le neago lelapa la gago go fihlelela mathata?
   …………………………………………………………………………………………
   …………………………………………………………………………………………
   …………………………………………………………………………………………
9. Ke di fe ditokelo tša lelapa mabapi le hlokomelo le thekgo ya ngwana wa go se itekanele monaganong?

   …………………………………………………………………………………………
   …………………………………………………………………………………………
   …………………………………………………………………………………………
10. Go ya ka kakanyo ya gago, ke eng seo se ka go go direga go thuša le go nea thekgo go ba lelapa go kona go dula le ngwana wa go se itekanelele monaganong?

    …………………………………………………………………………………………
    …………………………………………………………………………………………
11. Naa go dula le ngwana wa go se itekanele go ama maikutlo a gago bjang?

    …………………………………………………………………………………………
    …………………………………………………………………………………………
    …………………………………………………………………………………………
12. Ke a fe mathata ao lelapa le a fihlelago go tšwa go hlokomeleng ga ngwana yo a sa itekanelago monaganong?
    ....

……………………………………………………………………………………………………
……………………………………………………………………………………………………

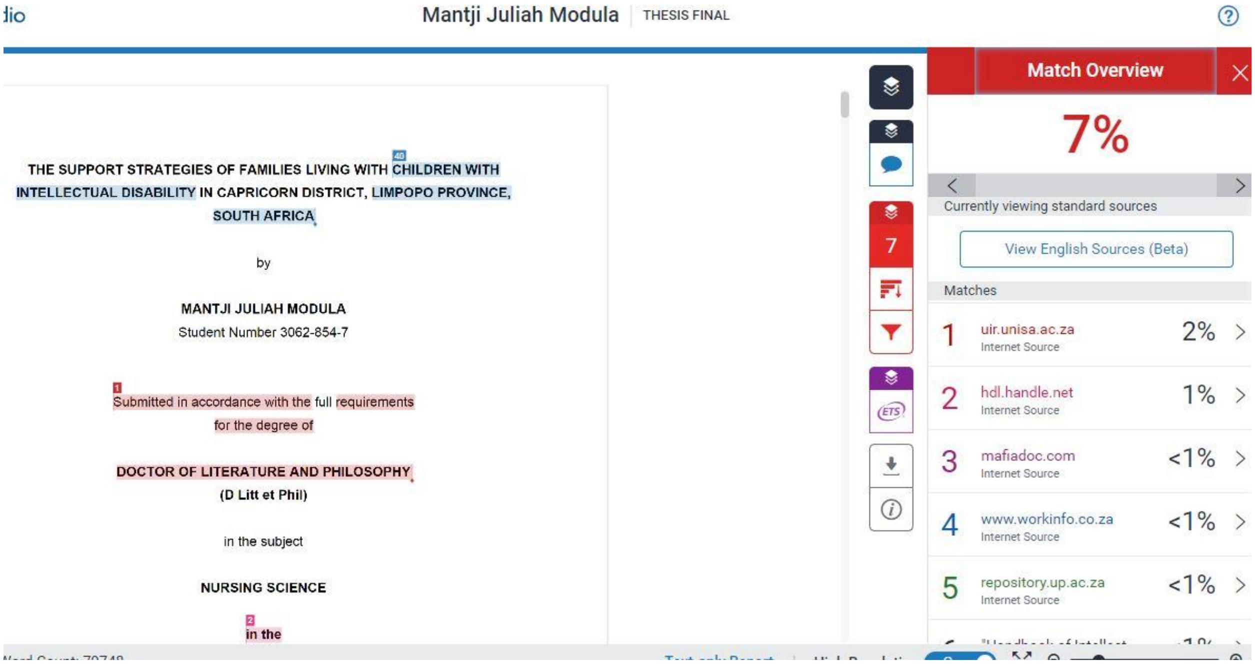
SERIPA SA BORARO: POLEDIŠANO YA GO AHLAAHLA KA SEBOKA

Ka boikokobetšo efa tshedimošo yeo e tletšego mabapi le diphihlelo tša go godiša ngwana wa go se itekanele monaganong

1. O kwešiša eng ka mabaka ao a hlolago go se itekanele ga monagano?
2. Hlalosa maitshwaro a ngwana wa gago
3. O hlohloletsa bjang ngwana wa gago ka gae?
4. Ke ditirelo di fe tšeo o di šomišago motseng wa geno go go thuša go hlokomela ngwana?
5. Go humanwe ngwana a le bokakang gore ga se a itekanela monaganong?

KE A LEBOGA

Annexure J: TURNITIN Report and Receipt



THE SUPPORT STRATEGIES OF FAMILIES LIVING WITH CHILDREN WITH INTELLECTUAL DISABILITY IN CAPRICORN DISTRICT, LIMPOPO PROVINCE, SOUTH AFRICA

by

MANTJI JULIAH MODULA
Student Number 3062-854-7

Submitted in accordance with the full requirements for the degree of

DOCTOR OF LITERATURE AND PHILOSOPHY
(D Litt et Phil)

in the subject

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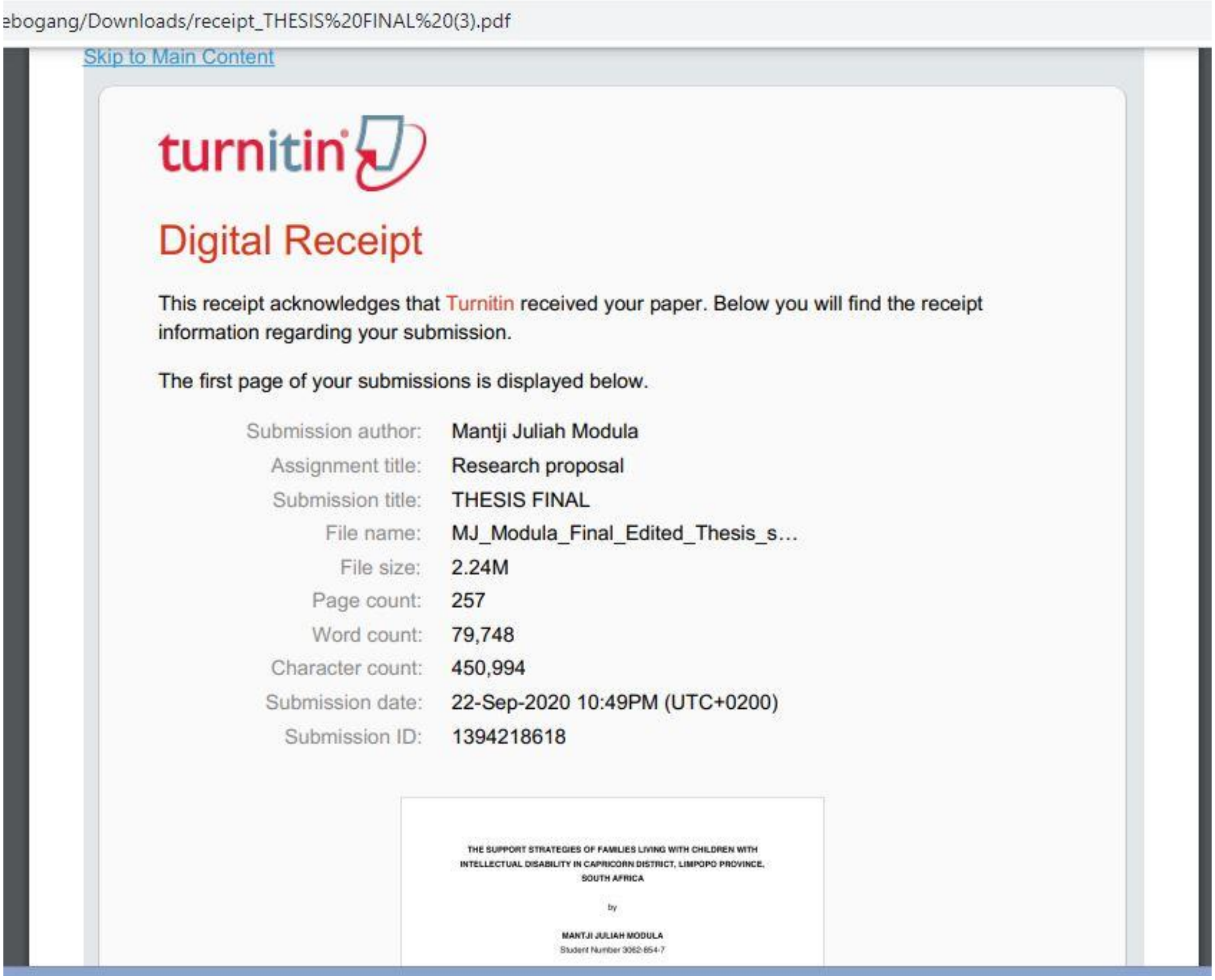

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Annexure K: Language Editing Certificate

7542 Galangal Street
Lotus Gardens
Pretoria
0008
03 August 2020

TO WHOM IT MAY CONCERN

This certificate serves to confirm that I have edited and proofread MJ Modula’s thesis entitled, **“THE SUPPORT STRATEGIES OF FAMILIES LIVING WITH CHILDREN WITH INTELLECTUAL DISABILITY”.**

I found the work easy and intriguing to read. Much of my editing basically dealt with obstructionist technical aspects of language, which could have otherwise compromised smooth reading as well as the sense of the information being conveyed. I hope that the work will be found to be of an acceptable standard. I am a member of Professional Editors’ Guild.

Hereunder are my particulars:

Jack Chokwe (Mr)

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