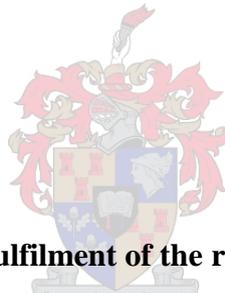


**PARENTS' PERSPECTIVES ON THE
DEVELOPMENTAL CARE NEEDS OF THEIR CHILD
WITH DOWN SYNDROME**

by

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HDE IV, B.ED (HON) SPECIAL EDUCATION, BA (HON) PSYCHOLOGY



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ABSTRACT

In the South African context, considerable remnants of the Apartheid era is still evident in low socio-economic areas. Parents, living in adverse conditions, namely, over-crowded housing, poor nutrition, lack of resources, as well as difficulties with access to health facilities, often do not have adequate education and information, regarding health and child development. The child's development cannot be separated from his/her social context; therefore, children with Down Syndrome, in low socio-economic areas, are at risk of not receiving appropriate, or proper, developmental care and support from parents to maximise their potential.

This qualitative case study research aimed to provide a better understanding of how parents, living in low socio-economic areas in Cape Town, South Africa, experience raising a child with Down syndrome. The over-arching goal of this research was an in-depth exploration to understand the perspectives and experiences of parents, in terms of meeting the developmental care needs of their child with Down syndrome. Purposive sampling was used, as parents with a child who has Down syndrome, were identified at a special school. A single-case (embedded) research design was selected that focused on the individual (parent), to understand their perceptions of the events. The data collection method included in-depth, semi-structured interviews with parents only. Content analysis was used as the method of data analysis.

The findings revealed that parents presented similarities, such as, relying on religion to help them cope, lack of resources and support services in the community, as well as access to these. Some of the themes that emerged included, the personal challenges of the parents, resilience and coping with the diagnosis, and the comorbid health conditions. The negative and positive experiences of the parents clarified their circumstances. The parents expressed that their experiences with their child instilled a unique knowledge in them, and therefore, they felt the need to share some advice with other parents, living in a similar context, with a child who has Down syndrome, or any other disability. In this study, the researcher offers suggestions to teachers who work with parents of children with Down syndrome, as well as other professionals, namely, doctors, psychologists and various therapists, who interact with parents of children who have Down syndrome.

OPSOMMING

Binne die Suid-Afrikaanse konteks is daar nog baie bewyse van die oorblyfsels van die apartheidsera wat binne die lae sosio-ekonomiese gebiede gesien kan word. Ouers wat leef in toestande soos oormatige behuising, swak voeding, gebrek aan hulpbronne, probleme met toegang tot gesondheidsfasiliteite, het dikwels nie voldoende opleiding en inligting rakende gesondheid en kindontwikkeling nie. Die kind se ontwikkeling kan nie van sy sosiale konteks geskei word nie en dit is om hierdie rede dat kinders met Downsindroom in lae sosio-ekonomiese gebiede die risiko loop dat hulle nie toepaslike of behoorlike ontwikkelingsorg en ondersteuning van ouers kry om hul potensiaal te maksimeer nie.

Hierdie kwalitatiewe gevallestudie-navorsing het ten doel om ons beter te verstaan hoe ouers wat in lae sosio-ekonomiese gebiede in Kaapstad, Suid-Afrika woon, ervaarom hul kind te verhoog met Downsindroom. Die oorkoepelende doelwit van hierdie navorsing was om die perspektiewe en ervarings van ouers deeglik te verken en te verstaan om die ontwikkelingsbehoefte van hul kind met Downsindroom te ontmoet. Doelwekkende steekproefneming is gebruik as ouers wat 'n kind met Downsindroom gehad het, is by 'n spesiale skool geïdentifiseer. 'n Enkele gevalle (Embedded) navorsingsontwerp is gekies wat op die individu (ouer) gefokus het om hul persepsies van gebeure te verstaan. Die data-insamelingsmetode het in-diepte semi- gestruktureerde onderhoude met ouers ingesluit. Inhoudsanalise is gebruik as die metode van data-analise.

Die bevindings het aangedui dat ouers ooreenkomste gehad het soos om op hul godsdienste staat te maak om hulle te help hanteer, gebrek aan hulpbronne en ondersteuningsdienste in die gemeenskap asook toegang tot hierdie. Van die temas wat na vore gekom het, was persoonlike uitdagings van die ouers, veerkragtigheid en die hantering van die diagnose en die gesamentlike gesondheidstoestande. Die negatiewe en positiewe ervarings van die ouers het hulle beter verstaan van hul omstandighede. Die ouers het uitgedruk dat hul ervarings met hul kind 'n unieke kennis vir hulle gebring het en daarom die behoefte gehad het om advies te gee met ander ouers wat in 'n soortgelyke konteks woon wat 'n kind met Downsindroom of enige ander gestremdheid het. Hierdie studie bied ook voorstelle aan onderwysers wat saamwerk met ouers van kinders met Downsindroom en professionele persone soos dokters, sielkundiges en verskeie terapeute wat met ouers met kinders met Downsindroom in wisselwerking tree.

DECLARATION

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third-party rights, and that I have not previously, in its entirety, or in part, submitted it to obtain any other qualification.

Student name: Debbie Lucillê Meyer (nee Loots)

Date: April 2019

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DEDICATION

This thesis is dedicated to my late mom and dad, Peter and Freda Loots.

ALWAYS IN MY HEART

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CHAPTER ONE

CONTEXT AND RATIONALE OF THE STUDY

1.1. Introduction

According to Haugaard (2008), Down syndrome (hereafter referred to as DS) is the most common chromosomal cause of mental retardation (currently known as Intellectual Disability). According to Gibson (2014), children with DS typically have mild to moderate cognitive delays, while many have speech and various motor delays. In South Africa, and more specifically Cape Town in the Western Cape, the data indicates that the prevalence of DS has been estimated as 1-in-670 live births (Scott, Futter & Wonkam, 2013). In an international study conducted, parents of children with DS indicated that their quality of life was affected in a positive manner, while caring for, and educating their child with DS (Buzatto & Beresin, 2008).

Barr, Govender and Rencken (2016) conducted a local study on caregivers' perspectives of raising a child with DS in Kwa-Zulu Natal. Their findings revealed that the initial feelings of caregivers, who have children with DS, were anxiety, upset and overall stress related to the diagnosis. Parents, generally, want to provide for their children, as well as help them succeed in life. Living in a low socio-economic area, or a poverty-stricken community, could complicate and affect parents, as well as how they provide and meet the needs of their children. Parents living in these low socio-economic areas, who have children with DS, face challenges, not necessarily experienced by parents with a typically developing child. These challenges include, finding appropriate day-care or educate, appropriate school placement for their child with DS, as well as serious health care challenges; possibly to access the health care system and everyday stressors of raising a child with developmental needs.

According to Mash and Wolfe (2010), the effects of childhood poverty and socio-economic disadvantages are detrimental to the overall development of a child, and could lead to learning difficulties. The child's development cannot be separated from its social context; therefore, children with DS, in low socio-economic areas, are at risk of not getting appropriate, or proper developmental care and support from parents, to maximise their potential.

The aim of the study was to provide a better understanding of how parents, living in low socio-economic areas in Cape Town, South Africa, experience raising a child with Down syndrome.

1.2. Context

I have worked with many families with children who have DS. My observation over the past 27 years was that the level of development always seemed different for the children with DS coming from low socio-economic areas compared to those children coming from affluent areas. This experience is part of my personal motivation for the study. Parents and families of children with DS who come from fairly affluent backgrounds or have a high income, have the luxury of accessing many resources including expert health care professionals, expert child care, support groups, parenting skills building sessions, etc. Children with DS coming from these affluent backgrounds, are often exposed to social media platforms such as WhatsApp, sms, Facebook, messenger and other forms of communication and social interaction. Many children who come from low socio-economic backgrounds are not that fortunate and have little to none exposure to any of these social media platforms, struggle to access basic resources such as private toilets, screening facilities and specialised health care facilities, parent support groups, etc. The exposure and access to these different resources can impact on children's health and learning, whether it be social or academic learning.

For various reasons, parents in poverty stricken-communities often do not realise that their children can live a functional and meaningful life. Life for these parents is very difficult due to the major challenges they face on a daily basis within their communities. According to Donald, Lazarus and Moolla (2014), parents in these situations (South African context) might feel demotivated and experience high levels of stress, which could impact on the development and care of the child, as parents could cease to meet the physical and psychological needs of their children. These conditions of poverty might have an even bigger impact on parents with HIV/AIDS. All of these risk factors are intensified by the presence of alcohol abuse, physical and/or sexual abuse, as well as family violence. The following quote highlights the plight of families living in poverty:

“Poverty is a pervasive barrier to participation worldwide and is both a cause and a consequence of disability. Families living in poverty are much more vulnerable to sickness and infection, especially in infancy and early childhood. They are also less likely to receive adequate health care or to be able to pay for basic medicines

or school fees. The costs of caring for a child with a disability create further hardship for a family, particularly for mothers who are often prevented from working and contributing to family income” (UNICEF: 2007, Innocenti Digest No. 13, p. iv).

Children with disabilities, and in this case children with DS, need proper developmental care and support from their parents, to assist in maximising their potential. The parents and guardians interviewed in this current research, live in low-socio-economic areas, with various challenges, as described above.

1.3. Rationale for the study

During the apartheid era of South Africa (pre-1994), disability was viewed as part of the medical model. This meant that people with disabilities were evaluated according to their medical condition, and this determined the services rendered to the individual (Republic of South Africa [RSA], 2015: p. 18). People with disabilities were excluded from schools, work places and social settings. The democratic elections in 1994 established a new era for South Africa. Restorative justice for all South Africans became the focus of the new government. The post-apartheid South Africa, through the constitution and the different policy documents, adopted the social model, and in doing so, aimed to realise the conceptual shift from the medical model to the social model. Many of the new policies across the different sectors, were aligned with the new Constitution of South Africa (Republic of South Africa [RSA], 1996), in order to promote and facilitate the full participation of people with disabilities.

One of the new policy documents implemented, to promote and ensure the inclusion, as well as the right to education for learners with disabilities was, The Education White Paper 6 that was drafted in 2000 (Republic of South Africa [RSA], 2001). The focus of this document was to remove barriers to learning, and provide support to all learners in need. The Screening, Identification, Assessment and Support (SIAS) document (Republic of South Africa [RSA], Department of Basic Education [DBE], 2014), is a policy document that acts as a guideline to assist and establish support for a learner with any barrier in his/her particular context. It also advocates for the involvement of the teachers, parents and learners.

Through the intervention of the teacher/s in class (SIAS form-Support Needs Assessment (SNA1) the possible barrier is identified, and the level of support needed is established. With

the assistance of the school-based support team (SIAS form- Support Needs Assessment (SNA 2), an application for the appropriate level of support needed is made to the district-based support team (Republic of South Africa [RSA], Department of Basic Education [DBE], 2014).

However, Adnams (2010) claims that, in the South African context, the legacies of inequalities from the Apartheid era can still be observed in the low socio-economic areas, as people with disabilities and intellectual disabilities are still marginalised in these areas. Children who live in South Africa are more vulnerable to experience traumatic events, such as abuse and violence; therefore, poverty, chronic stress and a lack of adequate nutrition may have a negative impact on their development (Johns & Adnams, 2016). Every child needs to be understood within his/her context, especially children with challenging developmental needs, as they might need additional support in the school, their family and the community. The individual with DS is already at a developmental disadvantage, and the contextual factors play a major role in his/her development.

A child is influenced by his/her community, culture and the broader society, and Bronfenbrenner's Bio-Ecological Model clarifies how this occurs (Landsberg, Krüger & Swart, 2011). All these systems that affect a child needs to be considered, particularly in a low socio-economic areas, as they might have more contextual challenges. Factors to deliberate on would be, the child in the family, the family dynamics, parenting styles, culture, the educational resources, the support system and services available to the parent, as well as accessing these services within this context. One also has to consider how the parents view and experience the complex set of demands to care for their child with a specific disability. Family income might also be an important factor affecting families' access to, and the use of external resources, such as community services, emotional support and parent information.

A typical example is access to support groups. Although there might not be any cost involved in attending a support group, the peripheral costs of transportation and child care might be a major problem for low income parents. For these families, there is the surmountable task of having daily child care and parenting support. Donald *et al.* (2014: p. 184) assert that it is difficult for parents living in poverty-stricken conditions, such as, over-crowded housing, poor nutrition, poor education, lack of resources, and lack of access to health facilities, to keep their children healthy. Therefore, the purpose of this current study was to explore, and ultimately understand, the parents' perspectives of the developmental care needs of their child with DS,

their experiences of what the available resources are in their community, the support networks and strategies required to assist parents in raising a child with DS, and how parents experience accessing resources, support and intervention within a very specific context, such as a low-socio-economic area.

1.4. Problem statement

“Families with children with disabilities are at higher risk of stress, financial disadvantage and family breakdown than other families. They are more likely to have a lower income, be socially isolated, stressed, separated or divorced and have poorer mental health than parents whose children are without disability. This culmination of risk factors makes these families more vulnerable to breakdown” (Muir & Strnadová, 2014: p. 922). According to Ahmed, Bryant, Ahmed, Jafri and Raashid (2013), Pakistani families of children with DS have built up resilience due to their daily struggles with their child’s disability. Many parents also have cultural and religious beliefs, regarding their child’s disability, while their view on disability is also influenced by their community.

According to a South African study, conducted by Greef and Nolting (2013), parents of children with developmental disabilities show markedly higher levels of parenting and life stress, than parents of typically developing children. The parenting stress associated with caring for a child with a disability, is strongly associated with the nature of the disorder, associated behavioural problems, as well as the demands of attention, due to daily care needs. Within the South African context, the availability of resources and facilities is limited for people with disabilities and their families (Statistics South Africa 2005 as cited by Greef & Nolting, 2013: p. 396). These families are expected to care for, and support their child with a disability, as well as pay for any professional services they need to access.

Donald *et al.* (2014) further expand on poverty in the South African context, and the effects on parenting. Parents living in these conditions (over-crowded housing, poor nutrition, poor education, lack of resources, difficulty accessing health facilities), often do not have adequate education and information regarding health and child development. These poor conditions, together with poor parental education, could lead to cognitive developmental risks for the children, among others. Factors that are considered indirect effects of poverty are “large families with many children, single parenthood, teenage parenthood and sick parents or

caregivers” (Donald *et al.*, 2014: p. 184). Considering the above research, it is clear to see that, within the South African context, there are many contextual barriers, or risk factors that impact child development and disability. According to Dreyer (2015: p. 18) the societal barriers specific to South Africa are “severe poverty, lack of access to basic services, lack of early intervention programmes, impact of HIV/AIDS, abuse, crime and teenage pregnancy, late admissions to school, violence and crime in neighbourhoods and at home, gender issues in cultural groups and society, negative and harmful attitudes to stereotyping of differences.” These are also considered to be more common in disadvantaged areas. Adnams (2010) adds to the above list of contextual risk factors that impact on disability, by referring to nutritional deficiencies, infectious diseases, including mother-to-child transmitted HIV/AIDS, Tuberculosis Meningitis (TBM), Foetal Alcohol Spectrum Disorder (FASD), violence and injury.

However, there seems to be limited evidence that focusses on how the parents from a low-socio-economic area in the Western Cape, South Africa, experience and meet the developmental care needs of their child with DS. Children with DS (in the South African context) who receive intervention early in life, tend to be slightly advanced, than those who do not get the early intervention. These children are influenced by the environment, and can flourish within homes where they are stimulated, loved, cared for, and have a variety of different experiences (Lloyd, 2015). Considering this as a protective factor for children with DS, people at grassroots level, namely, the parents, caregivers, neighbours, and other key role players in the community, need to be well-informed about the importance of developmental care, the impact of the lack of developmental care, as well as how knowledge could bring about significant change to the daily functioning of a child with DS.

This study could add valuable information, regarding the developmental care of children with DS in a low socio-economic area, to the current body of knowledge. The findings and recommendations made, could be of major significance to other parents in similar contexts, as well as teachers, psychologists and other professionals, who serve parents of a child with DS in this context.

1.5. Research questions and goals

The main research question that guided this study is as follows: What are parents’ perspectives

and experiences on the developmental care needs of a child with Down syndrome, while living in a low socio-economic area? The sub-questions are:

1. What are parents' perspectives on the developmental care needs of their child with DS?
2. What are the resources, support networks and strategies required to assist parents in raising a child with DS in a low socio-economic area?
3. How do parents experience accessing resources, support and intervention?

The over-arching goal was an in-depth exploration of the perspectives and experiences of parents in meeting the developmental care needs of their child with DS. Therefore, the secondary goals were:

- to gain understanding of how parents within a low socio-economic context cope in raising a child with DS
- to identify resources and support strategies required to raise a child with DS
- to provide information that would assist educational psychologist, educators, caregivers/parents and other professionals regarding the need for developmental care for children with DS living in a low socio-economic area.

1.6. Theoretical framework

The theoretical framework forms the underlying structure, or foundation of a study. This particular study was guided by Child Development Theories, in particular Bronfenbrenner's Systems Theory (Landsberg, Krüger & Swart, 2011: p. 56.), and child development, disability studies, as well as the impact of poverty on child development. Among the developmental theories is Jean Piaget's theory (Berk, 2009: p. 20), which includes four stages of cognitive development that, in essence studies the child's brain development and experiences, across four developmental stages, namely, sensori-motor, pre-operational, concrete operational, and formal operational. Each of these stages represent very distinct ways of thinking, and limitations in each stage, leads to developmental difficulties. This theory formed part of the foundation to this current study, as it provides a background to child development.

Cameron and Moore (2014, cited in Cameron, 2014) refer to disability studies as first perceived from a medical model point of view only, as well as how this view has caused much critique.

Disability studies, according to Mallet and Runswick-Cole (2014), rejects any model that views disability to be within an individual, as well as a social barrier to the individual. It was this new concept (the Social Model) and understanding of disability as a social barrier that was linked to important and relevant issues, such as equity, politics, economics and education. According to Dreyer (2015), the social model focusses on the removal of barriers (in the home, school and community); thereby, allowing individuals equal participation. In the post-apartheid era, the social model was adapted, with the focus on restorative justice and the removal of all barriers, including barriers to learning, as well as barriers in society for all people, especially people with disabilities. South Africa is lagging behind, with regards to addressing the inequalities that form part of the barriers. This current study aimed to shed light on how barriers within society, still hinder parents with children who have DS, and other disabilities.

The developmental systems theory that allows us to gain understanding of how these contextual factors impact the development of the child, is Bronfenbrenner's Bio-Ecological Theory, as illustrated below:

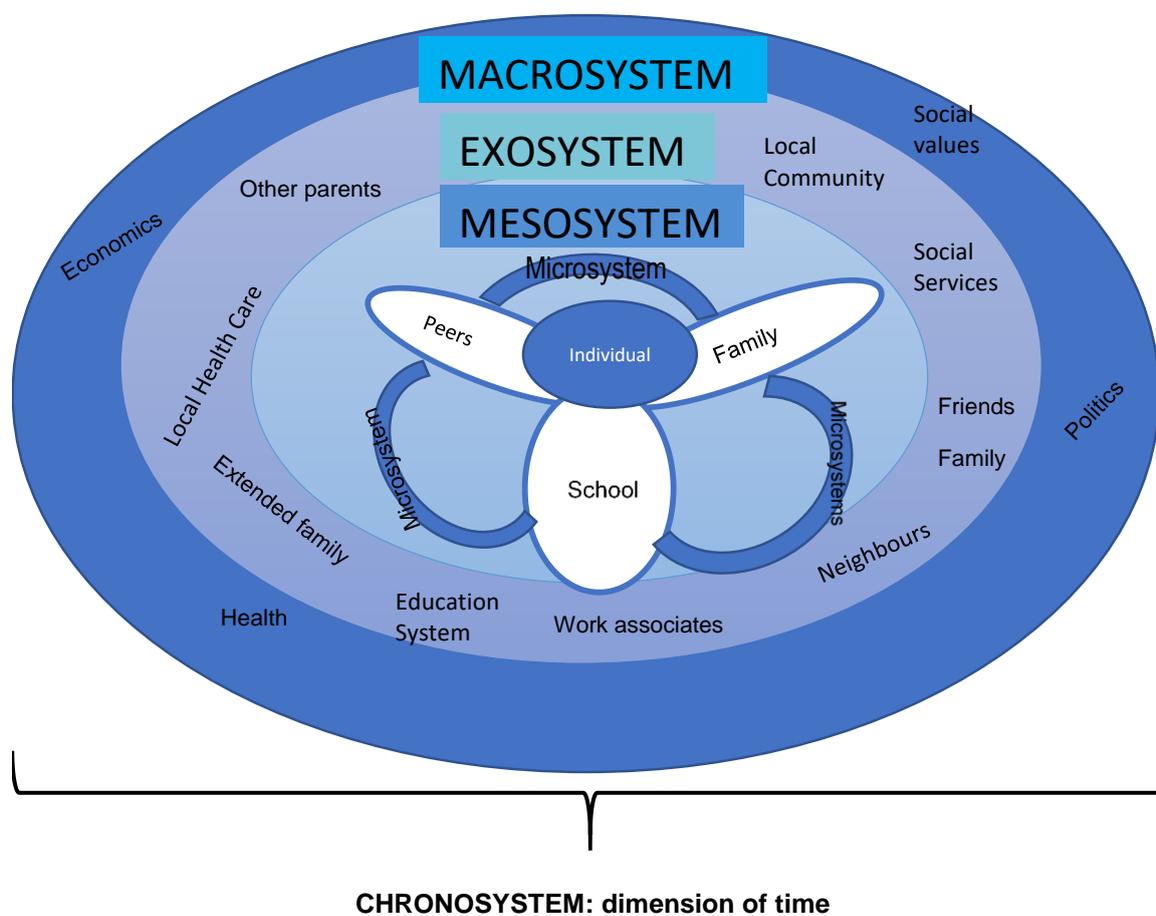


Figure 1.1. Illustration of Bronfenbrenner's Bio-Ecological Model (Landsberg et al., 2011: p. 13)

According to Landsberg *et al.* (2011: pp. 13-14), Bronfenbrenner's Bio-ecological Model broadened the understanding of contextual influences on human development. These contextual influences are described as complex environmental systems, which are all interrelated, with each one influencing the others. The various systems impacting on the child's development are: the Microsystem, Mesosystem, Exosystem, and Macrosystem, which interact within the Chronosystem, as explained in Figure 1.1. The Microsystem represents the interpersonal relations experienced by the individual, as well as the systems with which s/he interacts, such as the school, family and peers. It is considered the physical, social and psychological environment of the individual. The Mesosystem represents the relationship that exists between two or more of the microsystems. The Exosystem represents an environment in which the individual is not directly involved, but this system has an influence on his/her life. The Macrosystem has an impact on all the interactions of the different systems. It is also very specific to a culture, at any given time. The Chronosystem represents the dimension of time that relates to the different systems, and the impact thereof on the individual (Landsberg *et al.*, 2011). The focus for this current study was particularly on the family and parenting, which is at the Meso-systemic level.

In South Africa, specific contextual factors, such as HIV/AIDS, poverty, violence, trauma, are present, contributing to disability and child development. Curran and Runswick-Cole (2013: p. 92) refer to "spaces of poverty", and the life lived within these spaces, are critical for the understanding of how disability and childhood are constructed and lived. The Bronfenbrenner's Bio-Ecological Model is well suited for this study, as it allowed consideration of all systems discussed and described above. Regarding the parents interviewed in this study, these systems, namely, the Community Health Care Centre, the school, the education system, the extended family, as well as neighbours, have significantly influenced the manner in which the parents were able to meet the developmental needs of their child with DS. In support of the theoretical framework discussed above, this current study included literature on disability and poverty, as well as poverty and child development.

1.7. Research paradigm

According to Gavin (2008: p. 235), a paradigm "represents a position or viewpoint that defines how we interact with and understand the world around us." Punch (2014: p. 16-17) mentions the following main paradigm positions "positivism, interpretivism, and constructivism". Punch

elaborates on interpretivism, which is generally associated with qualitative research, as interpretivism “concentrates on the meanings people bring to situations and behaviour, and which they use to make sense of their world, these meanings are essential to understand behaviour”. This current study, therefore, has been aligned with the interpretive paradigm, as the parents, who were purposefully selected, shared their perspective of their world.

1.8. Research design

Research design is often described as a blueprint for a study. Yin (2014: p. 29) refers to components of a research design, which include “what questions to study, what data are relevant, what data to collect and how to analyse the results”. A case study was chosen as a suitable research design for the current study. A case study is described as a “qualitative research method in which the researcher provides a detailed description and account of one or more cases” (Christensen, Johnson & Turner, 2011: p. 374).

According to Punch (2014: p. 120), the case study aims to “understand the case in depth and in its natural setting, recognising its complexity and its context. It also has a holistic focus, aiming to preserve and understand the wholeness and unity of the case”. Each family in the study were viewed as a single case study. The interviews were aimed at sketching a holistic view and understanding of each case study.

1.9. Research methodology

According to Silverman (2010: p. 110), methodology refers to “choices we make about cases to study, methods of data gathering, forms of data analysis etc. in planning and executing a research study”. The methodology chosen for this study was of a qualitative in nature. Denzin & Lincoln (2011: p. 52) describe qualitative research as “an interpretive research approach that relies on multiple types of subjective data and investigates people in particular situations in their natural environment.” The researcher has attempted to understand the participants’ subjective perspective within their world.

The researcher employed the use of purposive sampling in this current study. According to Babbie (2010), purposive sampling occurs when a sample is selected on the basis of knowledge of a population, its elements and the purpose of the study. With the help of the school-based occupational therapist, the researcher recruited participants, who met the inclusion criteria. The

data were collected through semi-structured, face to face interviews. According to Punch (2014), interviews are observed to be an ideal way of accessing people's perceptions, meanings, definitions of situations, and their constructions of reality. An interview guide was used to navigate the interviews. Cohen, Manion and Morrison (2011) describe the interview guide as a tool to present the final data as systematic and comprehensive. All interviews were recorded with permission.

According to Cohen *et al.* (2011), qualitative data analysis has more of an interpretive nature, making the data more reflective than accurate. This method of data analysis is in line with the qualitative interpretive research paradigm that guided this current research. Content analysis was used. Cohen *et al.* (2011: p. 563) define content analysis as a "systematic set of procedures for the rigorous analysis, examination and verification of the contents of written data". The process of coding, allowed the researcher to identify themes, through similarities and differences, in a single case, as well as across different cases.

1.10. Credibility, Validity, Reliability and Dependability

According to Mathye and Eksteen (2016), the concepts of credibility, validity, reliability, dependability are linked to trustworthiness in qualitative research. These concepts are used to ensure that data will be collected and analysed in a rigorous manner, and therefore, ensure that the outcome of the research is credible and correct. Credibility, as described by Guba and Lincoln (1981), "involves establishing that the results of qualitative research are credible or believable from the perspective of the participant." According to Christensen *et al.* (2011: p. 362), research validity refers to the "correctness or truthfulness of the inferences that are or can be made from the results of a research study". These authors discuss validity strategies used in qualitative research, and mention, among others, descriptive validity and interpretive validity. Descriptive validity is "the factual accuracy of the account reported by the researcher". Interpretive validity for qualitative research is the "accurate portraying of the participants' subjective viewpoints and meanings". Reliability refers to "the stability of findings" (Silverman 2010: p. 360). Cohen, Manion and Morrison (2011) mention that the concept of dependability replaces the quantitative concept of validity.

Throughout the research process, the aim was to ensure, and incorporate the concepts of trustworthiness, as explained above. To ensure credibility, the participants were purposely

selected as they were able to provide the *insiders'* account of the topic under discussion. The processes of data collection and analysis were conducted as meticulously as possible, to further ensure the credibility of the study. To ensure dependability, the data collected through the semi-structured interviews were compared, in order to establish themes, similarities and differences.

1.11. Ethical considerations

Ethical agreements, as discussed by Babbie (2011), has been applied to ensure that the study is of an ethical nature, and that all the participants were treated in an ethical manner. The ethical considerations applicable to this case study included:

1. **No harm to the participants:** The researcher took all possible steps to guard against any form of psychological harm that could occur during the study. However, it was imminent that parents would endure some form of emotional trauma, in revisiting the birth and early years of the child's life. For this reason, the services of a counselling psychologist engaged to assist the parents should they need emotional support.
2. **Informed consent:** The participants were fully informed of voluntary participation, the right to withdraw from the study at any time (without prejudice), the purpose of the study and the possible emotional risks. Once explained, they had the opportunity to ask questions, to which answers were provided, and the consent forms, signed.
3. **Anonymity:** The researcher took all possible steps to ensure that the information in the study did not identify the families involved, by using pseudonyms.
4. **Confidentiality:** The researcher adhered to the rules of confidentiality, by protecting the identity of the participants, and not publicising their personal details and information. The data collected were viewed by the researcher and the research supervisor only. All data collected were transcribed by the researcher. All documents and data containing personal and confidential information, for example, hardcopies, recordings, were locked away in a code protected safe, to which only the researcher and supervisor had access. Electronic data were kept on a password activated laptop.

1.12. Concepts clarification

1.12.1. Intellectual disability

The Diagnostic Statistical Manual of Mental Disorders-Fifth Edition (DSM-5), provides

the following definition of Intellectual Disability: “Intellectual disability (Intellectual Developmental Disorder) is characterised by deficits in general mental abilities, such as reasoning, problem solving, planning, abstract thinking, judgement, academic learning and learning from social experience. The deficits result in impairments of adaptive functioning, such that the individual fails to meet standards of personal independence and social responsibility in one or more aspects of daily life, including communication, social participation, academic or occupational functioning and personal independence at home or in community settings.” (American Psychiatric Association, 2013).

1.12.2. Down syndrome

Gibson (2014: p. 1) refers to previous studies and defines Down syndrome as “a genetic condition in which an individual is born with an extra copy of the 21st chromosome”.

1.12.3. Development(-al) care

Developmental care is a “means of minimizing the possible deleterious effects of preterm birth and optimizing infant development. Developmental care encompasses a range of interventions comprising three key components: ongoing assessment of the neurodevelopmental condition of the infants reflected in individualized and dynamic care; reduction of environmental stressors, promotion of infant rest and maintenance of a positive energetic balance; and integration of parents in care activities” (Hamilton & Redshaw, 2009: p. 1738).

1.13. Chapter divisions

The research study was structured as follows:

Chapter	Description
1	Contextualises the research problem and provides an outline of the research process that will be conducted.
2	Presents an in-depth review of existing literature, focussing on the child development, Down Syndrome, Intellectual disability, poverty and disability, in relation to child development, parents' experiences of children with disabilities, early intervention, and support for parents of children with disabilities.
3	Provides a detailed report on the research process, which includes the research paradigm, the research design, the research methodology, as well as the ethical considerations.
4	A detailed presentation of the research findings and the discussions of themes that emerged.
5	Provides a summary of findings, strengths and limitations of the study, recommendations and concluding remarks.

1.14. Conclusion

In Chapter 1, the researcher aimed to provide the reader with an introduction, context and rationale for the study. In addition, the theoretical framework, which guided the research, particularly Bronfenbrenner's Bio-Ecological Model, was presented, as this was well suited for the current study. In this current study, the parents would discuss their perspectives and experiences of meeting the developmental care needs of their child with DS. These experiences would include the interaction and influences of the different systems within this model that affected the child and family.

A brief summary of the research process included the research design, paradigm and methodology used. In this chapter, the researcher also provided a basic understanding of the key concepts and aspects of the literature review, discussed further in Chapter 2. This chapter served as a basis for this current study; however, this study presented strengths and certain limitations; therefore, the researcher recommends further comprehensive research into the topic under scrutiny.

CHAPTER TWO

LITERATURE REVIEW

2.1. Introduction

According to Gray (2009: p. 99), a literature review “provides an up-to-date understanding of the subject, its significance and the structure, identifying significant issues and themes that present themselves for further research.” In addition, although there are gaps in current knowledge, guiding the development of research topics and questions, assisting future researchers to understand why the research was undertaken, its design and direction could assist others to replicate the research process. A literature review should reveal the underlying assumptions on which the research questions are based. Marshall and Rossman (2011), highlight that a literature review should reveal how this study would fill the identified need. Lastly, the literature review allows the research questions to be redefined, within the broader studies of the relevant topic.

In this chapter, therefore, the researcher presents an in-depth review of existing literature, focusing on child development, Down Syndrome (DS), Intellectual Disability, barriers to learning and development, disability, poverty, early intervention, experiences and perspectives of parents who have children with DS, and support for parents who have children with disabilities. To fully understand the concept of DS, the literature review was presented to construct a theoretical background to child development, the developmental and environmental risks to child development, and the significant implications of these risks to development. This structure would serve as the basis to define, discuss and expand the topic of Down syndrome.

2.2. Child Development

Much of what is known and understood about child development currently, has been shaped by researchers and developmental theorists of the past. There are many different models and theories to guide researchers through the different stages and phases of child development, and allow an insight into the conceptualisation of child development. Some developmental theories are included in Figure 2.1.

THEORIES OF DEVELOPMENT		
SIGMUND FREUD Psychoanalytic theory	ERIK ERIKSON Psycho-social theory of development	LEV VYGOTSKY Socio-cultural theory
URIE BRONFENBRENNER Bio-ecological theory	JEAN PIAGET Cognitive development theory	LAWRENCE KOHLBERG Moral development

Figure 2.1: Theories of development

Three of the above theorists are highlighted in this current study. Cognitive developmental theorist Jean Piaget believed that children's cognitive development was an "active and motivated process involving constant learning, unlearning and relearning" (Daniel, Wassell & Gilligan, 2010: p. 178). In Piaget's theory, reference is made to the child's brain development and experiences across four developmental stages, namely, sensori-motor, pre-operational, concrete operational and formal operational. Each of these stages represent very distinct ways of thinking, implying that a child's thoughts are developed as the child, successfully, passes through each stage. Below are the descriptions of the development within each stage.

Table 2.1: Piaget's stages of cognitive development (Berk, 2009: p. 21)

STAGE	PERIOD OF DEVELOPMENT	DESCRIPTION
Sensorimotor	Birth – 2 years	Infants "think" by acting on the world with their senses. The construction of knowledge based on action.
Pre-operational	2 – 7 years	Transition from understanding based on action to understanding based on symbolic representation such as words or pictures. Logical or abstract thinking not fully developed. Includes egocentrism, which refers to the child's ability to see others' perspective.
Concrete operational	7 – 11 years	When a child is able to classify things according to categories, they can apply logic to actions and they are able to conserve which means they are able to reverse and identify objects.
Formal operational	11 years on	At this stage the child should be able to reason in an abstract manner and think scientifically

Limitations within each stage leads to developmental difficulties. One major criticism of Piaget's theory is that no consideration was accorded to the influence of culture and context on the development of the child.

According to Townsend, Mayekiso and Ntshangase (2016), Vygotsky considered cognitive development of a child to be influenced by their cultural context and social interactions. The difference between Piaget and Vygotsky is, Vygotsky believed that children learn to communicate through social interaction with others around them; simply put, the child's social interaction is important to the development of the thinking process (Hardman, 2012). Vygotsky suggested that infants learn language through the interpersonal process with their caregivers.

The social stage is between birth and 3 years of age. During this stage the child uses language to express simple thoughts and feelings. The egocentric stage is between the ages of 3 and 7 years old, during which stage children use language to direct their own behaviour. They do this by talking aloud, termed, *external utterances*. These *external utterances* decrease as the child gets older. The child is now able to direct his behaviour in a silent manner. Vygotsky's theory further suggests that the child internalises these *cultural tools* of language, and develops the capacity to use language to think symbolically (Townsend, Mayekiso & Ntshangase, 2016: p. 64). According to Hardman (2012: p. 48), Vygotsky's theory is the basis for understanding cultural development, in context.

In order to understand the development of a child with intellectual disabilities, the development of the typical child needs to be understood. Therefore, the term, *development*, is firstly explored. Batshaw, Roizen and Lotrecchiano (2013: p. 244) elaborate on the concept of development by stating, "the complex, dynamic processes that make up child development can be described clinically by quantifiable milestones and qualitative features and can be divided into three 'streams' of development namely the motor, cognitive and neurobehavioural". Motor development includes, gross, fine and oral motor development. Cognitive development comprises language (receptive and expressive), problem-solving/non-language cognition. Neurobehavioural development includes social behaviour, adaptive emotional behaviour, self-regulation and mental status. According to Berk (2009: p. 4), the child's development is "as an area of study devoted to understanding constancy and change from conception through adolescence".

Berk (2009: p. 4) elaborates on child development, which occurs during the periods of development, which are, pre-natal, infancy and toddlerhood, early childhood, middle childhood and adolescence, as well as across the different developmental domains, namely, physical, cognitive and social-emotional. A description of what is expected during each period of

development, is provided in the following table.

Table 2.2: Periods of development (adapted from Berk, 2009: p. 5)

PERIOD OF DEVELOPMENT	AGE	DESCRIPTION
Pre-natal period	Conception to birth	Most rapid time of change
Infancy and toddlerhood	Birth – 2 years	Dramatic changes to the body and brain that support the emergence of a wide array of motor, perceptual and intellectual capacities. Beginning of language, first intimate ties to others. Infancy spans the first year and toddlerhood the second year.
Early childhood	2 – 6 years	Body becomes longer, leaner, motor skills are refined. Children become more self-controlled and self-sufficient. Thought and language expands. A sense of morality becomes evident. Children establish ties with peers.
Middle childhood	6 – 11 years	Children master new responsibilities, improved athletic abilities, participation in organised games with rules, more logical thought processes, mastery of basic literacy skills and advances in self-understanding, morality and friendship.
Adolescence	11 – 18 years	This period initiates the transition into adulthood. Puberty leads to an adult-sized body and sexual maturity. Thought becomes abstract and idealistic. Schooling is increasingly directed toward preparations for higher education and the world of work.
Emerging adulthood	18 – 25 years	These individuals have moved beyond adolescence, but they have not yet fully assumed adult roles.

The following Developmental domains are summarised, as discussed by Berk (2009: pp. 4-295):

- **Physical domain:**

This involves physical changes in the body, the development of the brain, and the effect of various factors, such as heredity, hormones and nutrition. The most important aspect in this domain is gross and fine motor development.

- **Cognitive domain:**

Cognition refers to how the individual acquires information about the world, by means of his senses, how this information is processed and interpreted, how it is stored and retrieved, as well as how the individual uses this knowledge to direct behaviour. It refers to how children come to know and understand their world, and includes language

development and problem-solving skills.

- **Social/Emotional domain:**

Social development involves the development of the individual's interaction and relationships with others. It also refers to the influences of society and significant other persons on the individual. It includes aspects such as, the development of attachment between the child and the caregiver, the expansion of the person's interpersonal relationships, the modelling of behaviour, and the development of relationships between the sexes. A very important aspect of social development is moral development. This involves the individual's view of right and wrong, and the development of moral judgements. Emotional development is characterised by the activation of the central and autonomic nervous systems, intestinal reactions and feelings such as, fear, anger, joy, etcetera, while the development of the child's affective experiences determines his involvement, or lack thereof, in components of the world. It determines the quality of meaning he attributes to the world, and the relationships he forms. This includes adaptive emotional behaviour. De Witt (2016: pp. 4-5) deliberates on the concept of development and highlights that researchers, over the years, have reached the following consensus regarding child development:

“all domains are interrelated and each one affects the other, normal development includes a wide range of individual differences which means that each child develops according to his own potential and characteristics, children participate in their own development which implies that they respond differently in influences, the historical and cultural contexts influences the child's development, later development is impacted by early experiences and development in childhood is connected to future development”.

In relation to this current study, children with DS fall short in each of Piaget's stages of cognitive development, which ultimately leads to developmental alterations. Vygotsy's theory describes language being learned within a social context. Although this might still be a challenge for a child with DS, the social interaction allows for increased language development of a child with DS. This might be one area that is considered a positive with a child who has DS. The developmental changes, as it occurs across the developmental periods and domains within a child with DS, as well as the risk factors,

are further integrated under the heading Down Syndrome.

2.2.1. Risk factors

There are 3 categories considered to be risk factors, which may influence child development, namely, “biological factors (pre, peri and post-natal periods, infections, birth conditions, mother’s health), established factors (genetic factors) and environmental factors such as family, social and institutional environments” (Correa, De Fatima Minetto, Cappellaro-Kobren & Moreira Cunha, 2015: p. 1285). Linking to this, Mash and Wolfe (2010: p. 27) emphasise the importance of contextual factors on child development, through the following statement:

“Contextual events in the family or school environment exert considerable influence over an individual’s course of development. A child’s development must therefore be considered in relation to multiple levels of influence such as the individual, family, community and culture”.

According to Donald, Lazarus and Moolla (2014), Bronfenbrenner’s Bio-Ecological Model (systems theory) describes the various systems that influence child development, in a social context.

The model (as discussed in Chapter 1) represents 5 systems, namely, the microsystem, mesosystem, exosystem, macrosystem and the chronosystem. For the whole system to function well, it is important that all parts function. The Microsystem represents the interpersonal relations experienced by the individual. These are the close relationships experienced by the child such as family, school and friends. It involves “roles, relationships and patterns of daily activities”. These activities shape facets of the socio-emotional, spiritual, moral and cognitive development. It is within the microsystem that a child experiences a sense of belonging and love. If the child is not supported at any level within this microsystem, it will negatively impact on the development of the child. This system which could potentially be a protective factor then becomes a risk factor. The Mesosystem represents the relationship that grows and exists between any of the microsystems mentioned above. This could refer to the relationship that started between the child’s family and the child’s friends or school. If a child is unsupported at home, or the school environment, it could affect the child’s learning, negatively (Donald, Lazarus and Moolla, 2014).

The Exosystem represents the system in which the child is not directly involved, but this system could still influence the child in some way. This could be the mother's work place, a teacher at school, the nurse at the clinic, etcetera. If a child with HIV/AIDS, or any other chronic illness, or s/he has a major family crisis and cannot access the health system, or social services, the crises in this system could have huge physical, emotional and psychological implications for the child. The Macrosystem refers to "the dominant social and economic structures, attitudes, beliefs, values and ideologies inherent in the systems of a particular society or culture. This includes democracy, social justice, equality, etc." These structures could have an impact on all the interactions of the different systems. It is also very specific to a culture, at a given time. The Chronosystem represents the dimension of time. Children develop over time, and interactions between the systems, over time, could have a significant influence on the development of the child (Donald, Lazarus and Moolla, 2014).

Concurring with Bronfenbrenner's Bio-Ecological Model is the perspective provided by Hardman (2012), regarding the systems affecting a child's development and learning. Hardman states that a family environment could affect a child's development. Family factors that contribute to child learning and development are, socio-economic status, parent-child interaction and the physical environment.

According to various research studies, parental socio-economic status, as well as their level of education, are "highly predictive of children's development and academic outcome" (Moletsane, 2004, as cited in Hardman, 2012, pp. 258-259). According to Hoffman et al. (1998, as cited in Hardman, 2012: p. 259), "children's access to health facilities, nutrition, and education, children's physical environment, neighbourhood, and peers, and the child-rearing patterns experienced, the size of the family, its authority structure and its stability", are all related to social class. Child development can be affected if there is poor parental interaction. Parents, who are alcoholics, abusive, absent from home for long periods, significantly impact the intellectual, academic and socio-emotional development of the child. Parental warmth, care and a good attachment relationship are imperative to the health and well-being of the child. In the family, it is the time, as well as the allocation of time that is valuable to the development of the child (Hardman, 2012: p. 259). The following table contains an overview of the effects of the environmental influences (contextual factors), during the periods of development, and

across different developmental domains, as discussed by Papalia, Wendkos Olds and Duskin Feldman (2008: pp. 59- 445).

Table 2.3: The effects of environmental influences on development (Adapted from Papalia, Wendkos Olds & Duskin Feldman, 2008: pp. 59-445)

ENVIRONMENTAL INFLUENCES	EFFECTS ON DEVELOPMENT
<p>Maternal factors (Prenatal):</p> <ul style="list-style-type: none"> - nutrition and maternal weight, - malnutrition, - physical activity and strenuous work, - drug intake, HIV/AIDS, - maternal illnesses such as rubella, diabetes, high blood pressure, thyroid deficiency, etc., - maternal stress, maternal age, - Outside environmental hazards such as air pollution, chemicals, radiation, foetal exposure to low levels of environmental toxins e.g. lead, mercury. <p>Paternal factors (Pre-natal):</p> <ul style="list-style-type: none"> - exposure to lead, marijuana or tobacco smoke, - large amounts of alcohol or radiation, pesticides or high ozone levels <p>All periods:</p> <ul style="list-style-type: none"> - Nutrition and living conditions-poverty - HIV/AIDS, malnutrition, - Poor parenting, abuse, - maltreatment and its effects, - negative factors regarding families, neighbours, cultures, etc. sleep, dental care, safety, accidental injuries, parenting styles 	<ul style="list-style-type: none"> - slow foetal growth, low birth weight, - Advanced paternal age is associated with severe rare conditions including dwarfism. - low IQ, - Exposure to radiation can lead to chromosomal malfunctions, Down Syndrome seizures. - Poor general health and well-being, - HIV / AIDS infected baby, infant death, stunted growth, - poor functioning throughout life, - Maltreatment can lead to cognitive delays, emotional and social problems. - Severe neglect from parents can have traumatic effects on the developing brain, problems in attachment and social relationships. - Child mental health disorders, childhood disorders and disabilities, development on language. - Developmental issues in infancy include developing trust, psychological issues in toddlerhood includes developing a sense of self, developing autonomy and moral development. - Health and respiratory problems, - Concerning body image (especially girls) can lead to eating disorders. - cognitive difficulties, scholastic performances

Considering what child development is, and the various risk factors across contexts and time, it is important to examine the following terms, as defined by Batshaw *et al.* (2013: p. 245), which describe the variations in attaining the atypical developmental milestones. These discrepancies demonstrate underlying developmental deficits:

- **Developmental delay:**

This refers to a significant lag in attainment of milestones in one, or more, areas of development, which are attained in atypical sequence, but at a slower rate.

- **Developmental dissociation:**

This refers to a significant difference in developmental rates between two of the major areas of development: gross motor, fine motor, problem-solving, expressive language, receptive language, and social/adaptive.

- **Developmental deviance:**

This refers to non-sequential unevenness in the achievement of milestones, in one or more streams of development.

2.2.2. Poverty and Child Development

Based on research, the concept of poverty differs from country to country, as each might use its own tool to measure poverty. There is no clear definition of poverty, and it is seen as a concept that could be measured from different perspectives, such as economic, political, cultural, etcetera. Eide and Ingstad (2011: pp. 3-4) refer to poverty as a “multidimensional concept that cannot be narrowed down to economic measures alone.” These authors further explore three aspects of poverty, as defined at The World Summit for Social Development in Copenhagen (United Nations [UN], 1995), namely absolute poverty, overall poverty and relative poverty:

- **Absolute poverty:**

“...a condition characterised by severe deprivation of basic human needs, including food, safe drinking water, sanitation facilities, health, shelter, education and information. It depends not only on the income but also on access to social services.”

- **Overall poverty:**

“...lack of income and productive resources to ensure sustainable livelihoods, hunger and malnutrition, ill health, limited or lack of access to education and other basic services, increased morbidity and mortality from illness, homelessness and inadequate housing, unsafe environments and social discrimination and exclusion. It is also characterised by lack of participation in decision making and in civil, social and cultural life ...”

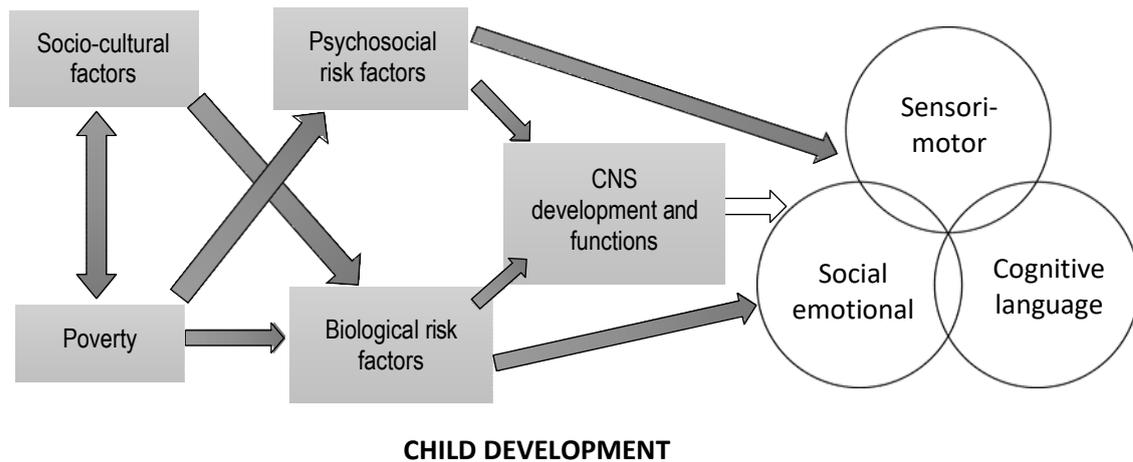
- **Relative poverty:**

“...poverty measured based on a poor standard of living or a low income relative to the rest of the society in question”.

According to Bremner and Wachs (2010: p. 124), research studies over the years have indicated that factors related to poverty, which influence infant development, include infant-parent attachment, quality of parenting, availability and quality of childcare and education during early childhood, accessing healthcare facilities, mental health status of parents, exposure to violence, fathers being present and child support, parental residence patterns, income sources, employment patterns, as well as neighbourhood and community characteristics. This correlates to Bronfenbrenner's Bio-Ecological Model, which connects these different systems to the child's development. "Biological and psychosocial risk factors associated with poverty lead to inequalities in early child development, which undermine educational attainment and adult productivity, thereby perpetuating the poverty cycle" (Walker *et al.*, 2011: p. 1326).

According to Walker *et al.* (2011), childhood risks associated with poverty, such as lack of stimulation or excessive stress can affect brain development. According to Mash and Wolfe (2010), the effects of childhood poverty and socio-economic disadvantages are detrimental to the overall development of a child, and could lead to learning difficulties. Neves (2012: p. 298) discusses poverty and child development in South Africa and asserts that socio-economic status plays a role in children's development. This author adds that rich parents "transmit" their "economic status" to their children, as their children not only inherit money and assets, but also have access to health facilities, educational opportunities, care and nurturing. This is not the same for children from poor parents, as these children grow up to be poor.

According to Neves (2012), the above factors impact on a child's physical, psychological, and cognitive development. Lipina and Colombo (2009: p. 3) contend that "Poverty increases a child's exposure to both biological and psychosocial risks that are most likely to affect developmental and social opportunities." Lipina and Colombo (2009) further illustrate the effects of poverty on child development (see Figure 2.2). The socio-cultural risk factors include, gender inequity, low maternal education and reduced access to services. Biological risk factors include, pre-natal and post-natal growth, nutrient deficiencies, infectious diseases and environmental toxins. The psychosocial risks include, parenting factors, maternal depression and exposure to violence. These risk factors affect the development and functioning of the central nervous system, and in turn, impact on the child's sensori-motor, the social emotional, and the cognitive development.



**Figure 2.2: Pathways from poverty to poor child development
(Lipina & Colombo, 2009: p. 53)**

2.3. Down Syndrome (DS)

As stated by Grieco, Pulsifer, Seligsohn, Skotko and Schwartz (2015: p. 139), Down syndrome was identified more than 150 years ago, by British physician John Langdon Down. According to Roberts and Richmond (2015: p. 404), Down syndrome (DS) is the most common developmental disability in the United States. Gibson (2014: p. 1) avers that the prevalence of DS in the United States is one-in-every-700 births. As mentioned in Chapter 1, research conducted in South Africa produced evidence suggesting that the prevalence of DS in Cape Town, in the Western Cape, has been estimated as one-in-670 live births (Scott, Futter & Wonkam, 2012).

According to Bremner and Wachs (2010: p. 315), the cause of DS, in 95% ID cases, is “the presence of an extra chromosome 21”. This statement concurs with the findings of a study conducted by Gibson (2014: p. 1) that DS is “a genetic condition in which an individual is born with an extra copy of the 21st chromosome”. Batshaw *et al.* (2013) adds to various research conducted over the years, and states that DS is a common genetic cause for mild to moderate Intellectual Disability, and associated with various health issues. Landsberg *et al.* (2011: p. 421) describe three types of DS, namely:

- **Trisomy 21:** This is a numerical deviation, where there are 47, instead of 46, because of three copies of chromosome 21 in every body cell. This type applies to 95 percent of people with DS.
- **Mosaic Down Syndrome:** This occurs when the numerical error starts in the second,

or subsequent cell divisions, producing some cells with 47 chromosomes, while others have the usual 46 chromosomes. These individuals have a mixture of the usual and the deviant types of cells in their bodies, and the relationship between these two groups of cells, determines how prominent the DS characteristics will manifest. Only 5 percent of people with DS are included in this type.

- **Translocation Down Syndrome:** This is a structural deviation, where part of the chromosome 21 becomes attached to another chromosome, manifesting as DS. In cases where the parents, or ancestors, had this kind of structural error, they could be a carrier of the condition.

A diagnosis for DS could be done by means of an in utero genetic screening, which allows for a pre-natal diagnosis (Republic of South Africa [RSA], Department of Basic Education [DBE], 2015; United Nations International Children's Emergency Fund [UNICEF], 2015: p. 27).

2.3.1. Developmental risks

According to Huiracocha *et al.* (2017: p. 488), DS is associated with distinctive observable characteristics (cognitive and behavioural phenotypes), and may involve delayed growth, added health problems, and difficulties in carrying out daily activities, as well as intellectual deficits.

Correa *et al.* (2015: p. 1286) concurs that children with DS are born with risks, such as their altered genetics, predetermined medical conditions, comorbidities, which come with the diagnosis of DS, as well as developmental limitations, or delays. Afifi, Aglan, Zaki, Thomas and Tosson (2012: p. 2647) explain that DS is “associated with intellectual disability, congenital malformations (especially of the heart), dysmorphic features and dysfunction of several organs.” Afifi *et al.* (2012) further state that growth delays of individuals with DS starts pre-natally, while DS is associated with complex disorders, such as “celiac disease, hypothyroidism and growth hormone deficiency.”

Some of the most common physical features associated with DS, as discussed by The National Association of Down Syndrome include: low muscle tone (a hypotonic appearance), small nasal bridge with a small nose, upward slant to the eyes, abnormal shape of the ear, an excessive joint flexibility, the little finger is curved inwards, small

skin folds on the inner corner of the eyes, excessive space between the large and second toe and enlargement of the tongue in relation to the size of the mouth (Batshaw *et al.*, 2013: p. 760).

Cuskelly, Hauser-Cram and Van Riper (2008: p. 105) state that the phenotypes (mentioned above) can include very precise patterns of strength and weaknesses, in areas such as, information processing, social interaction, expressive language, receptive skills, motor skills and motivation. In terms of cognitive development, if an individual with DS has an IQ ranging from 40-70, s/he falls in the mild to moderate range of intellectual disability. This is based on DSM-5 criteria for Intellectual Disability. The early childhood of such a child is marked by a decreased rate at which the developmental milestones are achieved that leads to a steady decline of IQ scores in the first few years.

Bremner and Wachs (2010) expand on the cognition, language, social and motor development of infants and young children with DS. In terms of language development, the receptive language skills in young children with DS emerge stronger than expressive language skills. Despite delays in language development, it would appear that some young children with DS show competence in certain areas of early non-verbal communication. Regarding the social functioning, many children with DS show appropriate mental age functioning in the area of early social connectedness. This would be different for young children with DS, who meet the criteria for comorbid Autism Spectrum Disorder, as they show impairment in this area of development. Young children with DS show major delays in reaching milestones in the area of motor development, as sitting independently, standing or walking could be delayed for up to 6 months. Deficits in motor planning has also been noted, which in turn leads to implications for adaptive behaviour and day-to-day skills.

According to Frank and Esbensen (2015: p. 719), the motor milestones are achieved by children with DS, but at a significantly later age, compared to the typically developing child. In addition, the observable behavioural traits of children with DS include, strengths in visual-spatial processing, deficits in relation to verbal processing, some motor functioning, as well as personal-care skills. According to Grieco *et al.* (2015), deficits in attention and executive functions, are associated with DS in early childhood, and become more evident as the child grows older. These authors further allude to the fact that

personality traits, such as a social and cheerful nature, is associated with individuals with DS, and these individuals are considered at a lower risk for developing psychopathology, compared to other children with an intellectual disability.

As DS is a cause of Intellectual Disability, deficits may be found in the following areas of development, as discussed in detail below:

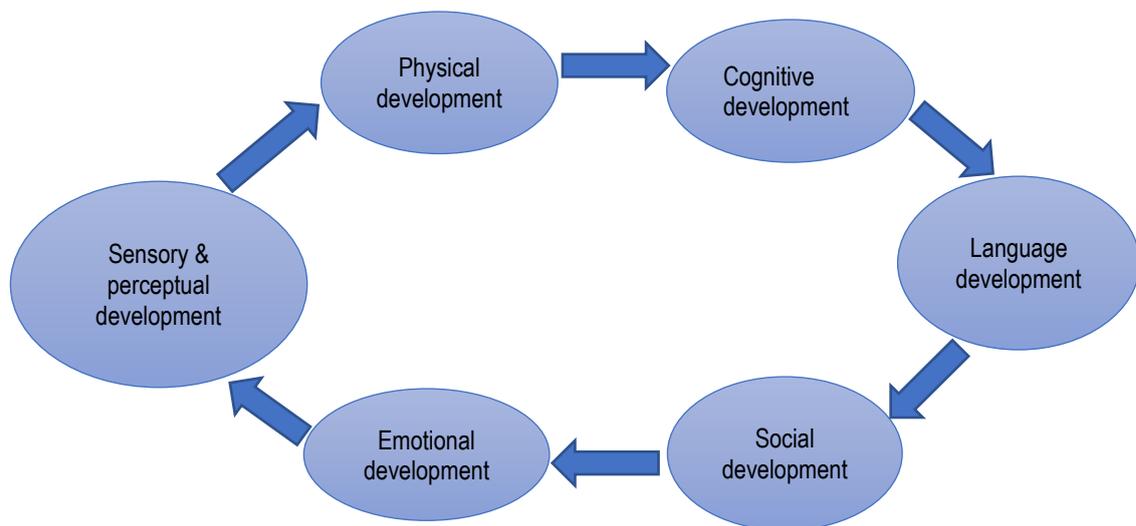


Figure 2.3: Interlinked areas of development (Johns & Adnams, 2016: p. 23).

2.4 Intellectual Disability (ID)

Since the early 1800's, ID was referred to as Mental Retardation (Sadock, 2007: p. 1138). Other terms, such as *mentally handicapped* and *mentally disabled* were also used, interchangeably. Many of these terms were perceived as negative, and were replaced, eventually, by terms that seemed more positive and acceptable to professionals and parents (Landsberg *et al.*, 2011). In the Diagnostic Statistical Manual of Mental Disorders-Fifth Edition [DSM-5] (American Psychiatric Association, 2013), the term mental retardation is replaced by the term Intellectual Disability. According to the (DSM-5), ID is a childhood disability as it has its onset during the developmental period of an individual. The Diagnostic Statistical Manual of Mental Disorders-Fifth Edition [DSM-5] (American Psychiatric Association, 2013: p. 33) provides the following definition: "Intellectual Disability (Intellectual Developmental Disorder) is a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social and practical domains". The DSM-5 refers to various levels of severity, such as mild, moderate, severe, or profound intellectual disability. The severity depends on what the adaptive functioning is of the individual, as this will determine the level of support required.

It is in the DSM-5 that the level of intellectual functioning is classified, using the IQ ranges, such as “mild-IQ level 50-55 to approximately 70, moderate-IQ level 34-40 to 50-55, severe- IQ level 20-25 to 35-40, profound-IQ level below 20 or 25.” (American Psychiatric Association, 2013: p. 33). According to the DSM-5, a diagnosis of ID requires both a clinical assessment and standardised testing of intellectual and adaptive functions. Mash and Wolfe (2010: p. 285) mention a two-group approach to mental retardation (ID), as proposed by researchers. These groups are, the Organic and the Cultural-Familial groups. The definitions, characteristics and causes of ID, as viewed by each group, are discussed below.

Table 2.4: The two-group approach to mental retardation (Mash & Wolfe, 2010: p. 285)

ID	ORGANIC GROUP	CULTURAL-FAMILIAL GROUP
DEFINITION	Individual shows clear organic cause of mental retardation	Individual shows no obvious cause of retardation. Other family members may have mental retardation.
CHARACTERISTICS	<p>More prevalent at moderate, severe and profound levels of retardation Equal or near-equal rates across all ethnic and socio-economic (SES) level.</p> <p>More often associated with other physical disabilities.</p>	<p>More prevalent in mild mental retardation.</p> <p>Higher rates within minority groups and low SES groups.</p> <p>Few associated physical and medical disabilities.</p>
CAUSES	<p>Prenatal (genetic disorders, accidents in utero).</p> <p>Perinatal (prematurity, anoxia).</p> <p>Postnatal (head trauma, meningitis).</p>	<p>Polygenic (i.e. parents of low IQ).</p> <p>Environmentally deprived.</p> <p>Undetected organic conditions.</p>

According to Adnams (2016), there is a high prevalence rate for conditions linked to the onset of ID in the pre-natal and developmental period. Adnams (2016, p. 11) refer to risk factors that increase the prevalence of ID, and mentions that environmental risk factors are more commonly associated with mild ID, whereas biological and genetic risk factors are more commonly found in severe ID. Therefore, a higher prevalence of mild ID is observed in lower socio-economic populations, compared to higher socio-economic populations. A poor environment will influence the development potential of an individual with severe ID, in a negative manner.

Donald *et al.* (2014: p. 365) further explain ID as a “wide range of problems related to intellectual functioning, all of which are characterised by a general, slow and limited ability to learn”. Areas affected are, skills in reasoning, language understanding and expression, memory, problem-solving, social and motor skills.

As discussed, children develop differently across different periods, domains and time. According to Johns and Adnams (2016), children with ID could take longer to reach their milestones, as they often have a developmental delay. Developmental delays could have different causes, such as genetics (Down syndrome), complications during pregnancy, or birth, in terms of prematurity and infection. Their levels of skills are usually lower than the child without ID. These low skills levels are across different domains such as language, learning and other daily living activities. Genetic and medical conditions may be linked with specific developmental outcomes in children with ID, such as motor impairments in children with cerebral palsy, and language impairment in children with DS.

Some children with ID develop better social skills, and cope better with social tasks, as well as day to day activities, than many other children. Jooste and Jooste (as cited in Landsberg *et al.*, 2011: p. 419) expand on the limitations in intellectual functioning and adaptive behaviour, as set out by the American Association on Intellectual Developmental Disabilities (AAIDD, 2010b), which refer to limitations in the following three types of skills:

- **Conceptual skills:** This refers to language, literacy, money, time, number concepts, self-direction.
- **Social skills:** These are interpersonal skills, social responsibility, self-esteem, naivety, social problems solving, the ability to follow rules, obey laws and avoid being victimised or harmed, etc.
- **Practical skills:** these are activities of daily living or personal care, occupational skills, health care, travel/transportation, schedules/routines, use of money use of telephone and other technologies.

These limitations could lead to an extremely challenging childhood, and for the parents, the experience could be as harrowing, while caring for their child with Intellectual Disability. Batshaw, Roizen and Lotrecchiano (2013: p. 293) clarify the areas of concern for a child with ID at different ages.

The researcher illustrates these concerns in Table 2.5, on the following page.

Table 2.5: Presentation of Intellectual Disability by age (Batshaw, Roizen & Lotrecchiano, 2013: p. 293)

AGE	AREA OF CONCERN
Newborn	Dysmorphism (structural abnormalities). Major physiological dysfunction (e.g. eating, breathing).
2 – 4 months	Failure to interact with the environment (e.g. parent suspects the child is deaf or has a visual impairment).
6 – 8 months	Gross motor delay (e.g. sitting, crawling, and walking).
18 months – 3 years	Language.
3 – 5 years	Language, Behaviour (including play). Fine motor (e.g. cutting, colouring).
5 + years	Academic achievement, Behaviour (e.g. attention, anxiety, mood, conduct).

2.4.1. Intellectual Disability: Risk factors

The American Association of Mental Retardation (AAMR - currently known as the American Association of Intellectual and Developmental Disabilities - AAIDD) introduced a *multifactorial system* to classify various risk factors, as illustrated in Table 2.6 below (Carr, 2007: p. 22).

Table 2.6: Risk factors for intellectual disability (Carr, 2007: p. 22).

TIMING	BIOMEDICAL	SOCIAL	BEHAVIOURAL	EDUCATIONAL
PRENATAL	Syndromes and behavioural phenotype Metabolic disorders Maternal illness Parental age	Poverty Maternal malnutrition Lack of access to prenatal care	Prenatal drug use Parental alcohol use Parental smoking Domestic violence	Parental intellectual disability without support Lack of preparation for parenthood
PERINATAL	Prematurity Birth injury Neonatal disorder	Lack of access to birth care	Parental rejection of caretaking Parental abandonment of child	Lack of medical referral for intervention services at discharge
POSTNATAL	Traumatic brain injury Malnutrition Meningoencephalitis Seizure disorders Degenerative disorders	Poverty Institutional upbringing	Lack of stimulation Child abuse Inadequate safety Chronic parent-child conflict Domestic violence	Delayed diagnosis Inadequate early intervention Inadequate special educational services Inadequate family support

Although many of the causes are globally applicable, in South Africa, many contextual causes are interrelated between the physical and genetic factors, which in turn, are related to the contextual disadvantages. Adnams (2010: p. 437) contends that, in the South African context, the legacies of inequalities from the apartheid era can still be seen in the low socio-economic areas, as people with disabilities, especially intellectual disabilities are still marginalised in these areas. Adnams (2010: p. 437) states that, although the causes of ID in South Africa have a similar prevalence to developing countries, there is no reliable data on the cause of ID in this country.

Emerson (2007, as cited in Adnams, 2010: p. 437) adds to research on the environmental factors and produces evidence of an association between poverty and intellectual disability. According to research, it is the combination of malnutrition, health risks, HIV/AIDS, alcohol abuse, parental stress, and the environmental deprivation (poverty) of a child, which are major risk factors to the overall development of the child, especially the cognitive development of the child. Adnams (2010: p. 437) expands on the contextual disadvantages that impact on disability and ID, in particular, by referring to nutritional deficiencies, infectious diseases, including mother-to-child transmitted HIV/AIDS, tuberculosis meningitis (TBM), foetal alcohol spectrum disorder (FASD), violence and injury. This author continues that the chronic malnutrition of children is associated with delays in intellectual development, besides other issues. Some of the risk factors are discussed in more detail in the following sections.

2.4.1.1. Trauma and Violence

According to Donald *et al.* (2014: p. 264), violence in South Africa is a huge concern, as this is considered a major problem that is affecting the youth. According to the stats of 2002, the World Health Organisation [WHO] concluded that the prevalence for violence in South Africa was very high. National research conducted by Donson (2008) and Ward (2012, both cited in Donald *et al.*, 2014: p. 264), revealed the high rates of crime, violence and injury to be even more serious. Johns and Adnams (2016: p. 12) contend that violence and injury in South Africa has led to high costs, in terms of public health. Traumatic brain injury (TBI) is the leading cause of death, and is a major preventable cause of ID in children, especially TBI, resulting from road accidents and physical assault. TBI also results in cognitive impairment in adolescents and adults.

2.4.1.2. Tuberculous (TB)

Landsberg *et al.* (2011: p. 371) refer to the prevalence of TB in poverty-stricken communities, as being a major concern in South Africa. Adnams (2010: p. 438) concludes that there is a high incidence of tuberculosis (TB) in the Western Cape region of South Africa. This author expands on TB and refers to TUBERCULOUS MENINGITIS (TBM) as "...the most severe form of extra-pulmonary tuberculosis. Children with a poor outcome develop severe neurological and multiple disabilities". TBM is viewed as one of the key factors for the development of moderate and severe intellectual disability in young South African individuals. According to Landsberg *et al.* (2011: p. 476), TB occurs more frequently in poor socio-economic conditions, and can spread rapidly, when people live in overcrowded areas, are malnourished, or live in close proximity to someone, who has untreated TB.

2.4.1.3. HIV/AIDS

Jansen and Stroud (2012, cited in Hardman, 2012) state that the HIV pandemic in the South African context is vast. According to these authors, HIV, as a health barrier, can cause abnormalities from birth, and children's developmental delays might only present at a later stage. The central nervous system of children with HIV is affected, which causes delays in their cognitive and motor developmental milestones. These delays impact on their skills needed for daily living. The dysfunction due to HIV, therefore, manifests in "deterioration of play, loss of acquired language, and loss of socially adapted skills." Jansen and Stroud (2012, cited in Hardman, 2012) further expand on the topic and state that children with HIV, for various reasons, are often separated from their primary caregivers. This experience of separation can severely impact the development of the child, as it might interfere with the attachment process between the child and the caregiver. This traumatic experience could also lead to a lack of social skills later. These HIV positive children develop at a slower rate, due to the above-mentioned emotional experiences and cognitive delays. According to Adnams (2010: p. 438), the leading cause of death for children under the age of 5 is HIV/AIDS. Children with HIV/AIDS have a high prevalence of cognitive impairment, deficits in visual spatial and motor skills, neurological impairments, seizures and encephalopathy.

Adnams (2010) further states that children on anti-retroviral treatment, were observed to be in the mild intellectual disability range. Children with HIV/AIDs are considered at risk, in terms of their development. According to Landsberg *et al.* (2011: p. 371), HIV infection through mother-to-child transmission may cause significant neurological damage in infants. Muir

2.4.1.4. Foetal Alcohol Spectrum Disorder (FASD)

One of the most tragic effects on children, which impacts on the whole development of the brain, is the abuse of alcohol by pregnant mothers. This is the cause of children being born with FASD (Landsberg *et al.*, 2011: p. 259). According to Adnams (2010: p. 438), there are many South African children, as well as adults with FASD, whose cognitive abilities are within the mild intellectual disability range. These individuals have deficits in executive function, as well as social and behavioural difficulties. This links to the intellectual and behavioural difficulties of people with FASD, as mentioned by Johns and Adnams (2016: p. 31). These include difficulties with memory, attention, understanding abstract concepts, planning and problem solving, having a low IQ, hyperactivity, speech and language delays, reading, writing and arithmetic (number processing) problems, poor reasoning and poor social judgement skills. These deficits are aggravated by the socio-economic factors. According to Donald *et al.* (2014: p. 259), a major concern for South Africa is that the prevalence rate for FASD has increased. FASD manifests as a range of physical, cognitive and behavioural symptoms. Johns and Adnams (2016: p. 13) further assert that the effects of FASD are permanent in child development. Considering this statement, it is unacceptable that so many South African children are affected by FASD, as research reveals that many of the contextual factors in South Africa are preventable.

2.5. POVERTY

Considering the context in which this study was conducted, namely, low-socio economic areas, it is important to highlight and refer back to “poverty and child development” (as discussed above). Poverty can have huge implications on a child’s intellectual development. Jansen and Stroud (2012, cited in Hardman, 2012: pp. 340-341) refer to the rural and informal settlements, which are “inhabited by the lower economic strata of the South African population.” According to these authors, people living in informal settlements, are exposed to poor living conditions,

and live in “survival mode”, which impact on their ability to develop proper skills. Socio-economic status, therefore, is a major barrier to child and adolescent development. According to Johns and Adnams (2016: p. 23), children who grow up in poverty, have less access to nutritional food, and fewer opportunities to engage in play activities, as well as tasks that stimulate their development. Children in South Africa are more vulnerable to experience traumatic events, such as abuse or violence. Poverty, chronic stress and a lack of adequate nutrition, therefore, may have a negative impact on their development. According to Adnams (2010, as cited in Donald *et al.*, 2014: p. 324) the physical link between children’s food intake, disease and brain development causes harmful intellectual effects. The social conditions of people living in poverty further add to the intellectual effects. Adnams (xxxx) further states that, under chronic conditions of poverty, the relationship of the mother and child could be affected, as the stresses of trying to survive, affect the energy of both the mother and the child. They, in turn, become less responsive to each other. The stimulation and interaction between mother and child, which is a needed factor for cognitive development, therefore, may be affected. Reducing poverty in South Africa, however, remains a major challenge. The following areas of development are affected by poverty:

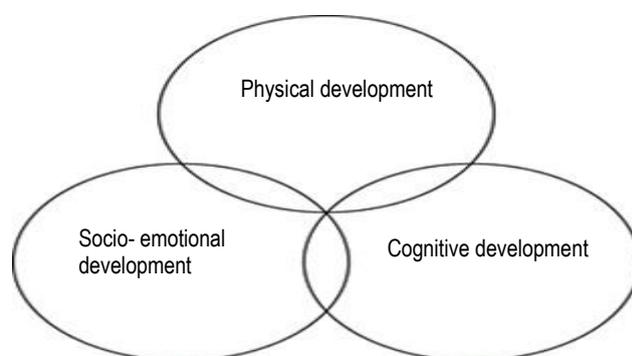


Figure 2.4: Areas of development affected by poverty

2.5.1. Poverty and disability

Barnes and Mercer (2013: pp. 249-250) expound on poverty and disability (as illustrated in figure 2.5), and refer to an individual living in poverty, as being more likely to acquire an impairment, which could lead to the person’s exclusion from society. Poverty can be perceived, among other definitions, as “social exclusion which affects the income, health, education, family life, social relationships and many aspects of families in poor communities”. Eide and Ingstad (2011: pp. 4-5) refer to individuals who are poor and often live in unhygienic conditions that include the lack of a sewage system, lack of clean water, as well as the lack of nutritious food, which could lead to malnutrition.

Malnutrition during pregnancy could cause developmental delays. These living conditions impact on the quality of life for these poor people, compared to the living conditions of those in more affluent communities. Eide and Ingstad (2011: pp. 5-6) expand on the overall impact of poverty on disability, by referring to poor people who often do not have the opportunities to change their environment, in order to avoid these health risks. Being poor, or living in poverty, could influence their access to the health system, which might not be the case for those who are financially able to access the health system. Additionally, accessing the health system could be due to the lack of health facilities in the immediate community, combined with finances for transport. In many of these low socio-economic areas, there might also be a lack of knowledge on how and where to access health services, or facilities.

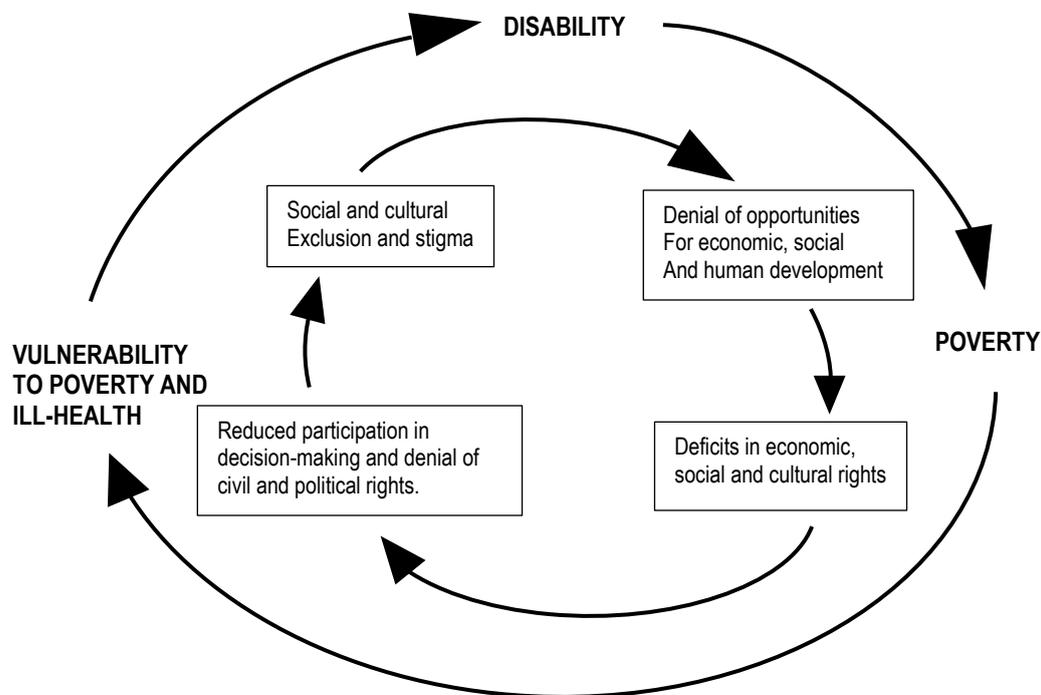


Figure 2.5: Linkages between poverty and disability (Barnes & Mercer, 2010: p. 250).

Adnams (2010: p. 437) refers to research conducted on the link between poverty and disability, as well as that within the South African context, there is not sufficient data to link the two concepts.

2.5.2. Poverty and barriers to learning

According to Hardman (2012: p. 259), poverty could affect children's educational stimulation. For example, families who live in poverty, cannot afford resources such as

educational toys, or writing and reading material that stimulate children's interest in education. The Department of Education (Republic of South Africa [RSA]. Department of Education [DOE], 2005: p. 10) states that among the "more frequent" causes of barriers to learning and development are, disability, as a barrier, language and communication, lack of parental recognition and involvement, socio-economic barriers, attitudes, as well as inadequate opportunity for programme-to-work. This highlights that poor socio-economic conditions could become a barrier to the child's learning and development. According to Donald *et al.* (2014: p. 324), about 10 percent of school-age learners experience barriers to learning. This could be higher in areas where there are extensive conditions of contextual disadvantages and poverty. Research has revealed that health and safety factors, in these contextually disadvantaged conditions, may cause an increase in physical, sensory, neurological, and cognitive developmental problems. Many mild developmental problems that could easily be corrected under advantaged conditions, are left untreated in disadvantaged contexts. Donald *et al.* (2014: p. 324) avers that one of the main areas of concern in the South African context (a phenomenon is not specific to South Africa only), is the very negative and detrimental relationship between poverty, malnutrition, HIV infection and cognitive development. In Figure 2.6 is an illustration of the negative cycle of poverty and the barriers to learning.

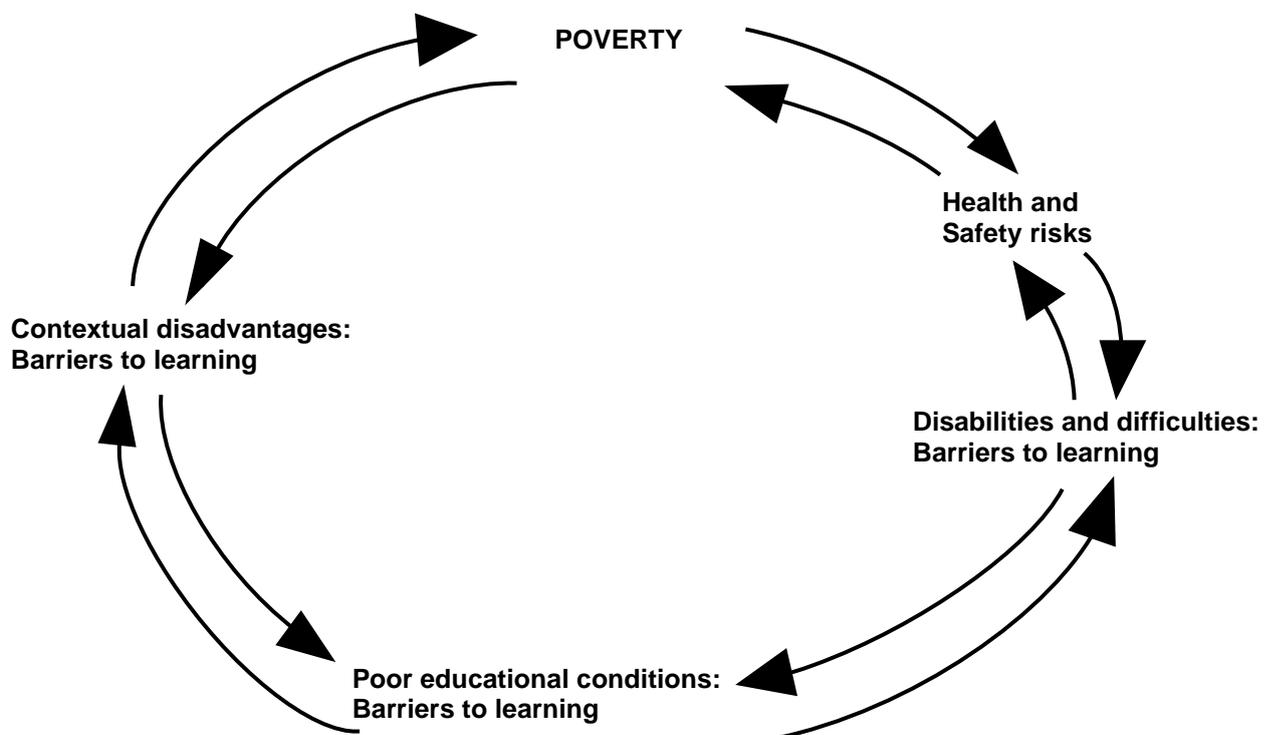


Figure 2.6: A typical negative cycle of poverty and barriers to learning (Donald *et al.*, 2014: p. 183).

In Figure 2.6), the researcher explains that children, living in poverty, are prone to health and safety risks, associated with poor nutrition, illnesses, infections and injury. Many of these health and safety risk factors could cause various disabilities, as well as learning difficulties. If the conditions for education are unfavourable, inadequate or poor, these conditions reinforce this negative cycle, as learners with barriers to learning cannot have their specific learning needs adequately met in over-crowded classrooms. This situation increases the level of poverty, because of contextual disadvantages. If Figure 2.6 is viewed anti-clockwise, it still proves to be true. Poverty, whether directly or indirectly, could lead to social problems, disabilities and other barriers (contextual disadvantages). These barriers could be exacerbated, to reinforce the poor educational conditions which the learner might experience. Dreyer (2015: pp. 18-19) explains the range of possible barriers, and groups these into four categories.

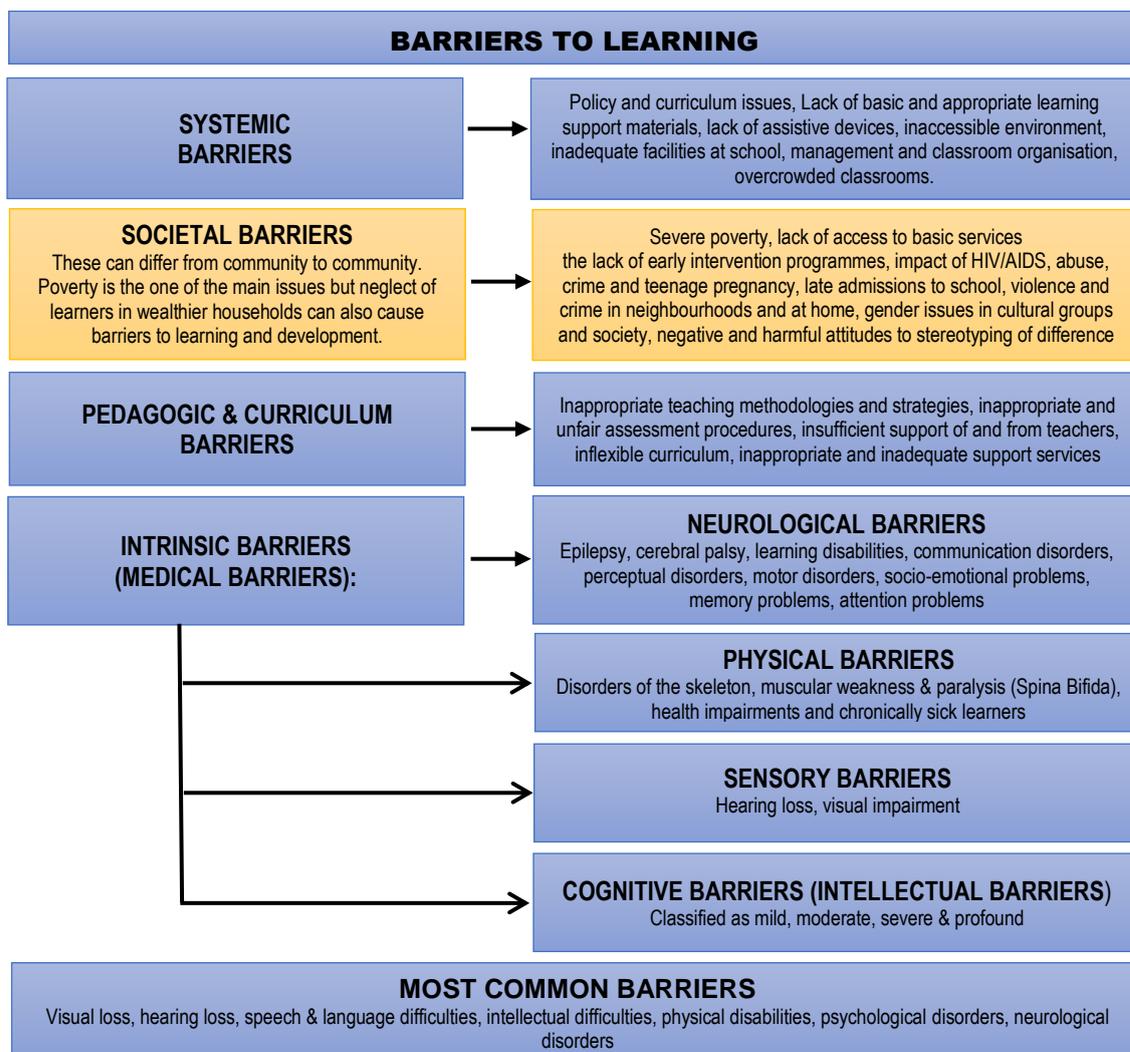


Figure 2.7: Barriers to learning (adapted from Dreyer, 2015:18-19).

In the old South African Education system, children with disabilities were assessed, based on the medical model; therefore, they were excluded and marginalised due to their disability. Johns and Adnams (2016: p. 56) explains the background to the education of South African children, during the apartheid era. Children were divided into 2 groups, namely, children with ordinary needs, who could be admitted to mainstream schools, and children with special needs, or disabilities, who needed specialised support. According to Johns and Adnams (2016: p. 56) children with special needs, or disabilities, were educated separately in special schools, often far from their homes. In addition, they were excluded from the education system; therefore, these learners “experienced learning breakdown within the system”. This system resulted in many learners with disabilities being refused access into a mainstream, or special school, and ending up on a waiting list, which added to the exclusion of learners with disabilities.

The new constitution, new policies and processes of transformation, brought significant changes to this previously segregated education system. The education system moved towards a more inclusive approach, and focussed on the right of learners with disabilities, which meant that children were not discriminated against, or treated as if the problem was “within them” (medical model). The inclusive education system adopted the social model which, as mentioned previously, perceived the barriers to learning as being in society, and not within the individual. The social model infers that the ordinary schools are not equipped to deal with classroom diversity, which forces learners, who experience barriers to learning, into special schools Dreyer (2015: p. 15).

Policy documents, such as the Education White Paper 6 (Republic of South Africa [RSA], Department of Basic Education [DBE], 2001), the School’s Act (Republic of South Africa [RSA], 1996), among others, were the guidelines for the new inclusive education system (Dzapasi, 2015: pp. 161-162). The Education White Paper 6 promotes the removal of barriers to learning and provides support to learners in need. The Screening, Identification, Assessment and Support document [SIAS] (RSA DBE, 2014), is a policy document that promotes inclusion of all learners. This document allows for the establishment of a level of support for learners who cannot cope with the mainstream school curriculum. The way in which learner needs are met within the inclusive education system, is illustrated in Figure 2.8 on the following page.

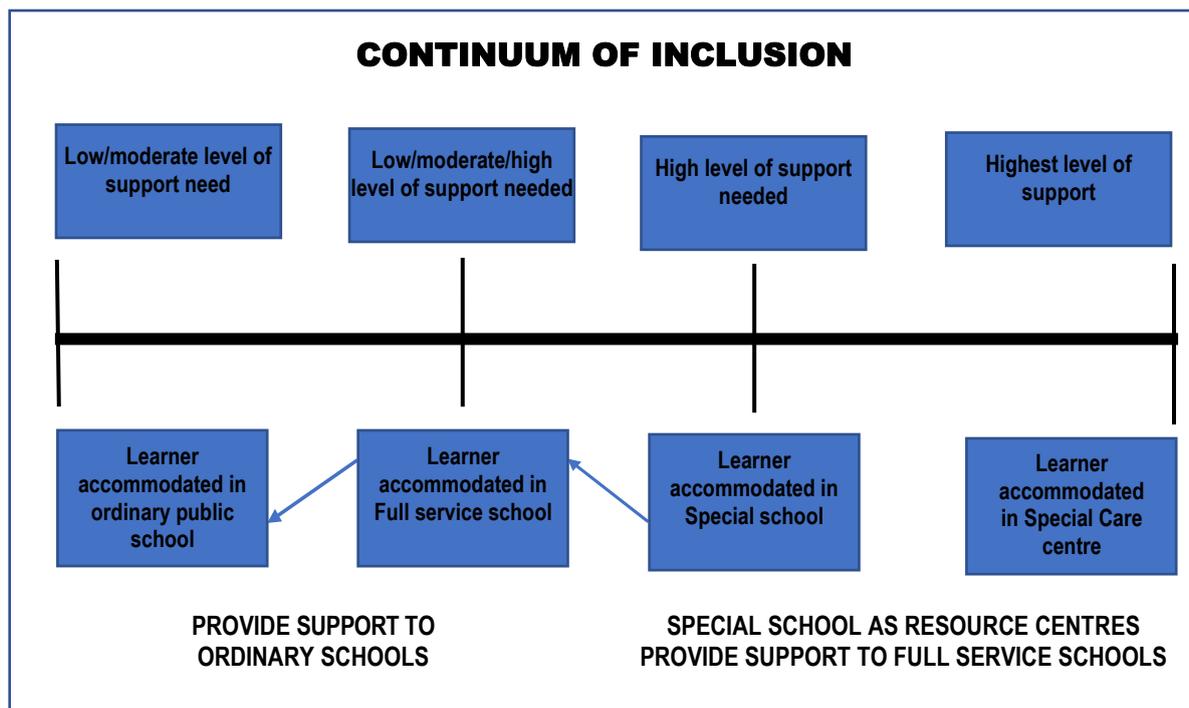


Figure 2.8. Continuum of Inclusion Model (Johns & Adnams, 2016: p. 58)

The above illustration is supported by the Department of Education (2010, p. 26). The implementation of the above policies remain a challenge, as South African contextual barriers could possibly create and contribute to the exclusion of many learners with disabilities. In this current study, the children with DS were in the high level of support needed, as they were accommodated at a special school.

The following statement refers to children with disabilities in Africa, but based on research, this is very much applicable to South Africa:

“Children with disabilities in Africa are among the most neglected groups in the policy domain as well as in the private sphere. The majority of these children face enormous economic, political, and social barriers that have an adverse impact on their physical, social and intellectual development and wellbeing. Many of them do not have access to the most basic needs such as health services and education experience multiple deprivations even within their family and are invisible in national policy agenda” (African Child Policy Forum [ACPF], 2011).

The child’s development cannot be separated from its social context; therefore, children

with DS in low socio-economic areas in South Africa, are at risk of not getting appropriate, or proper developmental care and support from parents, or care-givers, to maximise their potential.

2.6. Parenting: The effects of poverty

Bremner and Wachs (2010) state that the potential stress on parents, living in poverty, could become evident through the lack of maternal sensitivity, maternal depression, marital conflict, and maladaptive parenting styles, which in turn, could affect the development of the infants. The families living in poverty-stricken conditions, are at a higher risk for developing illnesses and infection. This is especially true for children in their infancy and early childhood stages. These families experience problems with resources, such as obtaining adequate health care, money to access basic medication, or paying school fees. Further challenges for the family include, meeting the basic needs of the child with a disability. These costs of providing for the basic needs of a child with a disability could be exorbitant (United Nations International Children's Emergency Fund [UNICEF], 2007, Innocenti Digest No. 13: p. IV).

Donald *et al.* (2014) further expand on poverty and its effects on parenting. Factors that are viewed as direct effects of poverty are, over-crowded housing, poor nutrition, poor education, lack of resources, as well as accessing these and other facilities, etcetera. For parents living under these conditions, it is very difficult to access health facilities, to keep their children healthy. These parents also often do not have adequate education and information on health and child development. These poor conditions, together with poor parental education, could lead to cognitive developmental risks for the children. Many of the factors considered indirect effects of poverty are, "large families with many children, single parenthood, teenage parenthood and sick parents or caregivers". Parents in these situations might feel demotivated, and experience high levels of stress, which could impact on the development and care of the child, as parents could cease to meet the physical and psychological needs of their children.

These conditions of poverty might have an even bigger impact on parents with HIV/AIDS. In addition, all of these risk factors are intensified by the presence of alcohol abuse, physical and/or sexual abuse, as well as family violence. These direct and indirect effects of poverty could lead to parental or caregiver stress. Figure 2.9, on the following page, is an illustration of poverty and parenting/caregiving

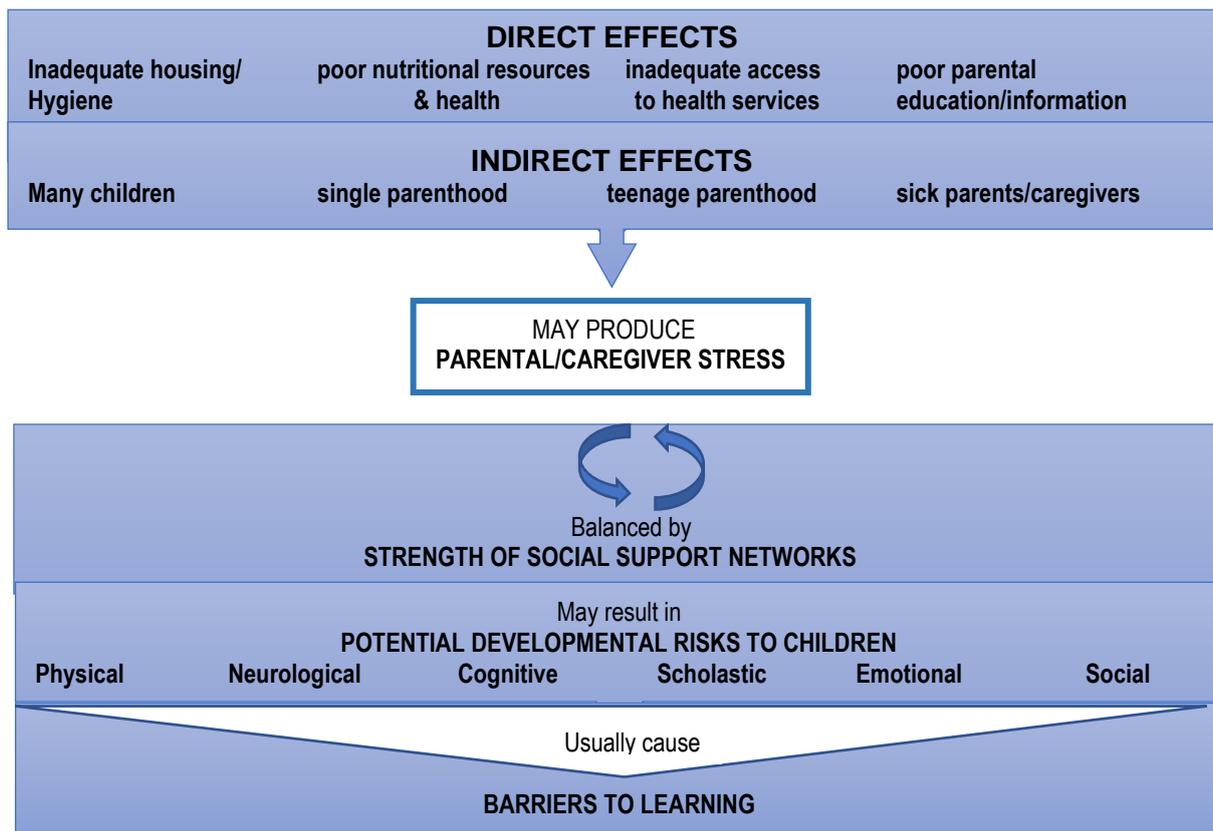


Figure 2.9 Poverty and parenting/caregiving (Donald, Lararus and Moolla, 2014: p. 184).

The South African Department of Health elaborated on the effects of poverty, affirming that people living in poverty are more at risk of developing mental health issues. According to the National Mental Health Policy Framework and Strategic Plan (2013-2020, p. 13), there is a distinct relationship between poverty and Mental ill-health. Poverty, such as economic deprivation, low education, unemployment, lack of basic amenities and housing including factors such as social exclusion, high stressors and malnutrition, could lead to mental health issues.

Considering all the above, South African parents living in these conditions who have a child with a disability, are therefore, at a greater risk of developing mental health illness, which, in turn, could affect the way they care for their child, or affect the way in which they have to meet the needs of their child.

2.7. Parents' experiences of children with disabilities

Phillips, Connors and Curtner-Smith (2017: p. 9) state that successful parenting is crucial to the child's intellectual, physical, social and emotional development. According to Phillips *et*

al. (2017), much research has been conducted on parenting of typically developing children, but not much exists on parenting a child with DS. Child-rearing has a significant impact on a child's development, regardless of the child's intellectual functioning.

“Families with children with disabilities are at higher risk of stress, financial disadvantage and family breakdown than other families. They are more likely to have a lower income, be socially isolated, stressed, separated or divorced and have poorer mental health than parents whose children are without disability. This culmination of risk factors makes these families more vulnerable to breakdown” (Muir & Strnadová, 2014: p. 922).

Carr, Linehan, O'Reilly, Walsh and McEvoy (2016: p. 69) state that, when parents who have a child with an intellectual disability, are told about their child's diagnosis, their initial response includes shock, anger and anxiety. This state of shock is followed by a process of denial and turmoil. Denial, according to Carr *et al.* (2016), could involve not believing the doctor's diagnosis and seeking a second opinion, in the hope that the initial diagnosis was incorrect. Emotional turmoil could include anger at the *loss* of the expected non-disabled child, and the anxiety of what the future holds. Anger may demonstrate through marital conflict, conflict between the parents and other children in the family, parents, or extended family members. Many children with intellectual disabilities, however, are not diagnosed until school-going age. Therefore, parents have to adjust and learn how to collaborate with others.

Carr *et al.* (2016) further explains that a major concern for the family of a child with a disability is receiving proper information about the diagnosis, as well as information regarding proper services available to the parents. It is further reported that the parents who have children with physical and intellectual disabilities, suffer more physical and mental health issues, compared to parents of children, who do not have a disability. These parents reported experiencing exhaustion, being overwhelmed, financial distress and severe sadness. According to Dabrowska and Pisula (2010: p. 266), parents who have children with developmental problems, indicate a higher level of parenting stress, compared to those parents with typical developing children.

Sijeeni and Barnard (2018: p. 76) conducted a study on how parents experience their circumstances when raising a child with a disability, especially DS, and produced evidence that every family's experience and perspective is different, when raising a child with DS. Hsiao and

Van Riper (2011: p. 182) state that the birth of a child with DS is a dire family incident that affects the child with DS, as well as the child's family members. These authors further state that previous research produced evidence that the birth of a child with DS was initially perceived as a tragedy to the family, but this view has changed significantly over the years.

Buzatto and Beresin (2008: p. 176) refer to factors affecting the physical and mental development of the child. According to these authors the most important consideration for a child with DS, is the stimulation the child receives from the close contact between the mother and child. As mentioned above, the development of a child with DS is much slower, compared to the typically developing child. Children with DS need daily stimulus and input. Therefore, it is of paramount importance that parents of children with DS commit themselves to meeting the developmental care needs of their child. Meeting the high demands of their child, as well as the ongoing complete dedication from the parents on a daily basis, could be exhausting and life changing. Parents and families experience changes in family dynamics, functionality of the family as well as emotional changes. These life-altering changes can affect parents' quality of life in some way or the other.

“The World Health Organization (WHO) defines ‘quality of life’ as the perception that individuals have of their position in life within their cultural and value systems, their objectives, expectations and concerns” (Buzatto & Beresin, 2008: p. 176). Buzatto and Beresin (2008) add that these changes in the parents' quality of life are directly linked to various factors, which include accepting their child's limitations, the manner in which they were informed of their child's condition or diagnosis, not being able to receive adequate information, and adjusting to the changes in their daily routines.

The findings of a local study, conducted by Barr, Govender and Rencken (2016: p. 929) on caregivers' perspectives of raising a child with Down Syndrome in Kwa-Zulu Natal, revealed that the initial emotions of caregivers who had children with congenital disorders, such as DS, included anxiety, upset and overall stress, related to the diagnosis. This experience is compared to bereavement, as it resembled the loss of a *normal* child. These parents are expected to accept the inevitable life changes required to raise their child. They have to accept their *reality*. These authors claim that not understanding the diagnosis, or condition, leads to insufficient knowledge for the parents, or caregivers, on how to raise the child. When comparing children with DS to children with other disabilities, Skotko, Levine and Goldstein (2011: p. 2335)

formulated the term, *Down Syndrome advantage*. This term implied positive responses from the families of children with DS. These included families of children with DS having a closer and more harmonious relationship, their parents experiencing less stress, their fathers and mothers reporting that they were more confident about their parenting skills, parents claiming that their children were easier to raise, and parents reporting more marital satisfaction.

The limitation to this study, though, was that these comments could possibly have been from parents with a higher parental income, or parents with more maturity. Phillips *et al.* (2017: p. 9) refer to the above study, and state that parents, who had children with DS, reported higher levels of stress, depression, and were reportedly struggling with their child's behavioural issues. Brewis, Briggs, Fourie, Hodgkinson and Pahl (2012: pp. 13-15) conducted a national study, and contributed to understanding the perspectives and experiences of parents of children with DS. The results of this study included the following: some mothers were given a late diagnosis; mothers did not get in-depth information regarding DS; a few mothers were dissatisfied with the doctors, as well as the information shared; some mothers were not provided with a variety of support options; support often came from other mothers, who had children with DS; and the onus was placed on the public health care system, to provide and equalise the information shared with the mothers. Some mothers also indicated that there was a lack of information regarding early intervention, and the information was not very specific to their situation, regarding their child with DS. Mothers, who were able to access private health care services, were referred to a variety of professionals.

These mothers received better and adequate information relevant to their situation. Mothers, who accessed the public health care services, reportedly, received more negative information, and not much practical guidance. It was the sole responsibility of the parents to access the relevant information and services. Based on the above research, there appears to be many similarities for parents who have children with disabilities. Parents selected for this current study emanate from similar contextual backgrounds as described above. The aim of this current study was to explore what their experiences of raising a child with DS might be, compared to literature.

Considering the theoretical framework for this current study, Bronfenbrenner's Bio-Ecological Model, the concepts and heading, as discussed above, have been put into context below. In the microsystem, which represents the interpersonal relations as experienced by the individual, as

well as the genetic influences, the concept of child development can be discussed. It is within this microsystem that the biological and environmental risk factors affect the development of the child, as it can alter the life of the individual born with DS. In this current study, the education of the parents, their mental health, as well as their financial status, affected the development of the child. The relationship between the child, parent, school and community impacted hugely on the developmental needs of the child with DS. It is within this system that the child with DS could be nurtured, and where early intervention could add to a positive upbringing of the child. A child with DS, who is not supported at any level within this microsystem, will experience a negative impact on his or her development. A positive experience within the microsystem, together with the mesosystem, could potentially be a protective factor, and enhance the cognitive, physical and emotional needs of the child with DS. In the South African context, the mesosystem and macrosystem in many communities, unfortunately, add to the negative influences on development. The lack of social, economic, and psychological support within communities could lead to many developmental risk factors. The communities of the participants created a negative environment that, ultimately, contributed to the parents failing to meet the needs of the child with DS. As mentioned, the effects of the educational, social, economic, and political inequalities within the South African landscape, still has effects on the people of South Africa, especially for the parents who have children with disabilities.

2.8. Early Intervention: The key for development in children with disabilities

According to Lerner and Johns (2012: p. 229), the early years of a child's life is fundamental to learning, especially for a child with a disability. Lerner and Johns (2012) emphasise the importance of parents and family investing in a young child's life, as s/he has to master certain skills by the time they enter formal education. This correlates with child development theories, emphasising that children start to learn from birth. Children's intellectual skills need to be developed in these early years. The term "Early Childhood Development (ECD) means the process of emotional, cognitive, sensory, spiritual, moral, physical, social and communication development of children from birth to school going age" (Republic of South Africa [RSA]. (2008: p. 28). According to Pasensie (2012: p. 1), early childhood development interventions contribute to increased academic registration, increased nutrition and health status, reduced drop-out rates and grade failures, enhanced social and emotional behaviour and overall improvement in verbal and intellectual.

The Department of Education addresses early childhood development and refers to the pivotal role of ECD providers, in the early intervention of child development. The aim of ECD providers is to focus on trying to meet the basic development needs of all young children, including all barriers to learning within the system. These barriers include poor nutrition, disintegration of family units and health related issues (RSA, DBE, 2014: p. 4). According to the practitioners, who participated in a study on children with disabilities, the early intervention and inclusion of any young child with a disability into ECD programmes or facilities, is a fundamental part of development for children with disabilities. It allows them to develop the needed skills for their school-aged years, when they have to integrate into the education system.

Based on studies, children with disabilities, who were included into the ECD programmes, seemed to cope better in society, generally, including their ability to integrate better with other typically developing children. Early inclusion of children with disability also seemed to have a positive effect on the way these children were accepted into the communities, and brought about tolerance to diversity, as well as the most needed appropriate nutrition, which has a significant effect on the healthy development of all young children (Department of Basic Education 2015 and UNICEF, 2015, p. 60).

Jover and Torres (2009: p. 27) highlight the relationship imbalances that could exist when families have children with DS. They mention that characteristics such as, Intellectual Disability and decreased muscle tone in children with DS, could lead to babies having difficulties in the sensory domain, as well as in initiating activity. This might cause them to take longer to process information and evaluate their surroundings. Therefore, they respond slower, which could be perceived as non-reaction to a situation. Consequently, the primary objective for early intervention is to enhance the relationship between the child and the parents. Lloyd (2015) addresses many issues regarding early intervention of children with DS. Among these is the importance of early intervention for children with DS. The following general definition is provided for intervention in child development “the “coming between any negative, disabling effects that a developmental delay or disability might have on the developmental process in general”. Lloyd (2015) further discusses how many definitions do not include the child’s environment, and gives the following definition for early intervention:

“Early intervention consists of multidisciplinary services provided for developmentally vulnerable or disabled children from birth to age three years and their families. These programmes are designed to help child development, lessen

possible delays, work with existing problems, prevent further worsening of the condition, limit possibility of getting additional disabling conditions, and/ or help the family to adapt the way they function. The goals of early intervention are achieved by giving developmental and therapeutic services for children, and support and instruction for their families.”

The aim of early intervention is to minimise the impact of the condition on the child's development. Early intervention for a child with DS could help the child to be at an advantage, compared to those children with DS, who do not receive intervention. Lloyd (2015) further states that individuals with DS are easily influenced by their environment, and function optimally in homes, where they experience appropriate stimulation, love and care. This positive experience and daily stimulation could prevent the slow progress of the child with DS. A child's development cannot occur in isolation. The child's environment includes the family, school, community, culture and society, which are all factors that contribute to the positive, or negative, development of a child. Lloyd (2015: p. xx) provides the following reasons for early intervention:

- The first patterns of learning and behaviour that influence the rest of the development are set down in the early years;
- There are certain critical periods during the early years, when a child is most responsive to learning experiences;
- A child's environment and early experiences, particularly if these are nurturing or depriving, have a major effect on development and learning. Both greatly influence the degree to which a child reaches his/her full potential;
- Parents usually need help in establishing constructive patterns of parenting with a young child experiencing a disability, as well as in providing adequate care, stimulation and training for their child, during the critical early years, when basic developmental skills should be acquired; and
- Early intervention implies some socio-economic benefits, as prevention or early treatment of developmental problems in young children may reduce the need for management by society of more serious problems later. It could be cost effective.

Correlated to the above, are the benefits of early intervention, as discussed by Lerner and

Johns (2012: pp. 229-230) which include:

- It helps children with disabilities, as it accelerates the cognitive and social development and reduces behavioural problems.
- It benefits the families of young children with special needs, because, as families become empowered, they play an integral part of the child's learning process. It allows families to be more confident and optimistic.

Life for parents and care-givers of children with DS can be difficult due to the major challenges they face in their communities. They often do not realise that their children with DS could live a functional and meaningful life, and that early intervention is key to their child's development.

2.9. Support for parents of children with disabilities

According to Stroh, Robinson and Proctor (2008: p. 155) parents who have a child who is developmentally delayed, need support and understanding in order to help them make sense of their different parenting experience compared to other parents. Stroh *et al.* (2008) suggest that, when parents work together with other parents, teachers and other professionals, they could respond positively to their child's needs. In this manner, they can share ideas and relevant information that could assist each other.

The Convention on the Rights of Person's with Disability (CRPD) declares to the following:

“Persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities” (UNICEF, 2013, p. 13). This implies that families of children with disabilities need support to enhance inclusion of persons with disabilities. This includes setting up a home conducive to early intervention from as early as the first few days of a child's development. Emphasised in the CRPD is the right of such families to “an adequate standard of living, adequate food, clothing and housing.”

According to Huiracocha *et al.* (2017: p. 488), studies conducted on parenting children with DS suggest that professionals should communicate with parents in a more thoughtful manner, and parents should have more social support. This could bring about acceptance and positive

changes in the family. Marshall, Tanner, Kozyr and Kirby (2014: p. 365) state that people with DS could live longer, be more sociable, and that early access to support networks and resources for the parents would guarantee a good start in life, and improved outcomes. Families need support with the educational, social and medical interventions for their child. Families living in low socio-economic areas experience problems with accessing support and resources. This includes accessing health care and the services of other professionals (UNICEF, 2007: p. IV).

2.10. Conclusion

The aim of this study was to explore the parents' experiences of the developmental care of their child with DS. Parents from low socio-economic areas, who have children with DS in a particular special school, were invited to participate in this current study. In Chapter 2, the researcher's aim was to place the current study in a particular context and literature framework. The research design for this qualitative study, as well as the research methodology, are explained in the next chapter. The research methodology includes the method of sampling, data collection and data analysis.

CHAPTER THREE

RESEARCH DESIGN AND METHODOLOGY

3.1. Introduction

The focus of this chapter was to describe the research design and methodology of this current study, as set out in Chapter 1. This qualitative research study was explained by discussing the research paradigm, research design and the context of the study. The research goals were revisited to add to the coherence of the chapter, and the study as a whole. A more detailed discussion on the methodology, sampling, data collection and data analysis is included in this chapter, as well as the Ethical considerations regarded.

3.2. Research Questions

As set out in Chapter 1, the main research question is: What are parents' perspectives and experiences on the developmental care needs of a child with Down Syndrome while living in a low socio-economic area? The sub-questions that guided the case study are:

1. What are parents' perspectives on the developmental care needs of their child with DS?
2. What are the resources, support networks and strategies required to assist parents in raising a child with DS in a low socio-economic area?
3. How do parents experience accessing resources, support and intervention?

The secondary goals allowed for an in-depth exploration of the perspectives and experiences of parents, in meeting the developmental care needs of their child with DS. These goals included the following:

- To gain understanding of how parents within a low socio-economic context cope in raising a child with DS.
- To identify resources and support strategies required to raise a child with DS.
- To provide information that would assist educational psychologist, educators, caregivers and other professionals regarding the need for developmental care for children with DS living in a low socio-economic area. The interview guide was drawn up to collect relevant and comprehensive data to answer the research questions.

3.3. Research Paradigm

According to Denzin and Lincoln (2011: p. 91-103), a qualitative, interpretive research paradigm (also known as the Interpretive framework and Constructivist paradigm) implies that researchers “gain understanding by interpreting subject perceptions.” These authors further explain the concept, *paradigm*, as a “basic set of beliefs that guides action.” A paradigm, according to these authors, includes four terms, namely, ethics (axiology), epistemology, ontology and methodology. The dimension axiology, discussed below, is described by Cohen, Manion and Morrison (2011: p. 33).

Table 3.1. The 4 dimensions of the interpretive paradigm

DIMENSION	CONSTRUCTIVISM/INTERPRETIVE PARADIGM: gain understanding by interpreting participants’ perceptions
Axiology (Ethics and values) How will I be as a moral person in the world?	<ul style="list-style-type: none"> • These are principles and meanings conducting research, and the ethics that govern these such as beneficence, respect and the promotion of social justice.
Ontology What is the nature of the reality?	<ul style="list-style-type: none"> • Multiple realities exist and are dependent on the individual • Internal reality of subjective experience
Epistemology What is the relationship between the researcher and that being researched?	<ul style="list-style-type: none"> • Transactional/subjectivist created findings. • The philosophical belief that people construct their own understanding of reality, we construct meaning based on our interactions with our surroundings. • Empathetic, observer subjectivity
Methodology What is the process of the research?	<ul style="list-style-type: none"> • Hermeneutical/ dialectical: individual constructs are elicited and refined hermeneutically, and compared and contrasted dialectically, with the aim of generating one or a few constructions on which there is substantial consensus. • Interactional, interpretation and qualitative

(Adapted from Denzin & Lincoln, 2011: p. 102-105; Cohen, Manion & Morrison, 2011: p. 33)

3.4. Research Design

The qualitative interpretive paradigm guided this research, and therefore, also the research design selected. The research design chosen for this study was a case study. A few definitions of a case study include:

“an in-depth, multi-faceted investigation, using qualitative research methods, of a single social phenomenon” (Outhwaite & Turner, 2007: p. 111).

“an empirical enquiry that investigates a contemporary phenomenon (the ‘case’) in-depth and within its real-world context especially when the boundaries between

phenomenon and context may not be clearly evident” Yin (2014: p. 16).

According to Cohen *et al.* (2011: p. 289), one of the advantages of a case study is that it can observe the impact on an individual, or unit of analysis, within a natural setting, thereby conceding that the context has an influence on the individual, or the case. These authors further expound that “contexts are unique and dynamic; hence, case studies investigate and report the real life, complex dynamic and unfolding interactions of events, human relationships and other factors in a unique instance.” A case study research design, therefore, has some key features that will allow the researcher to focus on the individual, seeking to understand their perceptions of events and it is very detailed. According to Kumar (2011: p. 126), a case study has the unique characteristic of a “flexible and open-ended” method of data collection and data analysis. The method of data collection in this case study was semi-structured interviews, with the purposive sampling of parents, who have children with Down Syndrome. Cohen *et al.* (2011: p. 291) explains a single case study design to “focus on a critical, an extreme, unique, representative, typical or revelatory case”.

In the research design for this current study, it was clear that, although similarities were noted among the participants, each had their unique and dynamic context in which they raised their child with DS. The interviews, which allowed for open-ended and flexible data collection, has produced insight into the complex and colourful world of the parents. Yin (2009: p. 46) illustrates four types of case study designs, namely, a single case design, a multiple-case design, a single-case: embedded, and the multiple-case: embedded (see Figure 3.1.). For this current study, the researcher implemented a Single-Case (Embedded) Design.

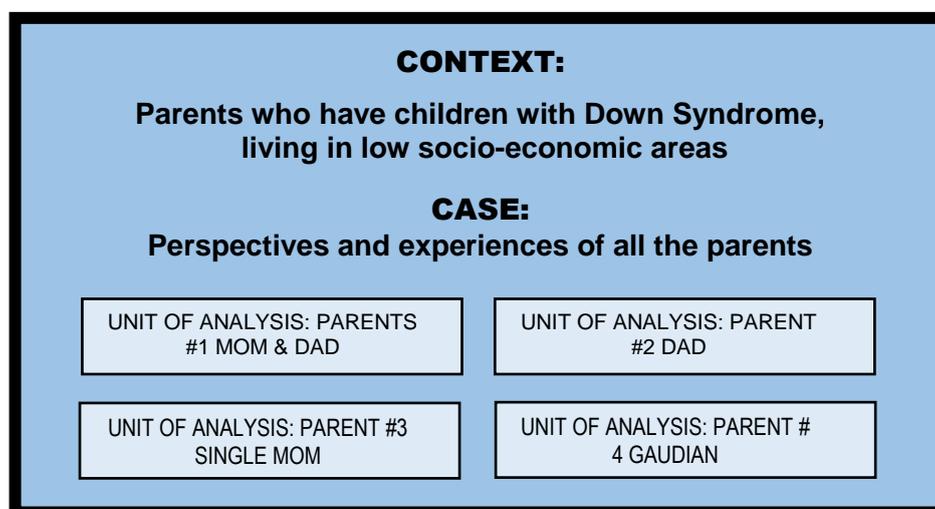


Figure 3.1. This study illustrated within its context, its case and the sub-units of analysis

The context of this study was the low socio-economic areas where the parents lived, most of them close to the special school, which their children attended. The primary case was the perspectives and experiences of the all the parents, and the multiple units of analysis refer to the perspectives and experiences of individual parents. This type of design will ensure the aspect of trustworthiness in this qualitative research.

3.5. Research Methodology

The methodology of this current study was qualitative in nature and aligned with the interpretive paradigm. According to Kumar (2011: p. 104), the “main focus of a qualitative research is to understand, explain, explore, discover and clarify situations, feelings, perceptions, attitudes, values, beliefs and experiences of a group of people”. Outhwaite and Turner (2007: p. 580) describe qualitative research as “a multi-method in focus, involving an interpretive, naturalistic approach to its subject matter.” This implies that the researcher studies the *subjects* within their natural settings. This corresponds with Creswell’s (2009: p. 175) list of the characteristics of qualitative research, as follows:

- **Natural setting**, implies that qualitative researchers collect data in the field at the site where participants experience the issue, or problem, under study. In the natural setting, the qualitative researchers have face-to-face interaction over time.
- **The researcher is the key instrument**, who collects data through examining documents, observing behaviour, or interviewing participants; therefore, the researcher does not rely on questionnaires, or instruments, developed by other researchers.
- **The participants’ meaning**, implies that the researcher keeps a focus on learning the meaning, which the participants hold about the problem, or issue, not the meaning that the researchers bring to the research.

This study used purposive sampling, as only parents, who had children with Down syndrome, were included. The data collection was in the form of semi-structured interviews with the parents, and were recorded with permission from the participants. The data analysis included content analysis, as this method of data analysis included analysing the content and the context. Using the method of coding, the themes, similarities and differences were identified from the data collected.

3.5.1. Sampling

Participants for this case study were purposefully selected. Cohen *et al.* (2011: p. 156-

157) refer to purposive sampling as a distinct feature of qualitative research, as the researcher gets to “hand-pick” the participants, based on their specific knowledge being sought. Purposive sampling is used to “focus on specific, unique issues or cases” and to “access knowledgeable people i.e. those who have in-depth knowledge about particular issues.” The selection criteria for the participants/parents was having a child with DS, attending the special school where the study was conducted. Many of the parents of children attending the special school, do not originate from privileged backgrounds. The purpose of this type of sampling was to gain an understanding and insight into the parents’ perspectives of the developmental care of their child with DS.

3.5.2. Data Collection

In a qualitative interpretive research design, researchers use in-depth interviewing, which is acknowledged as the “construction site of knowledge where two individuals discuss a theme of mutual interest” (Marshall & Rossman, 2011: p. 142). Cohen *et al.* (2011: pp. 411-413) describe an interview as a process that enables the participants, because it allows them to express how they interpret their context, and how they perceive circumstances from their point of view. The interview, therefore, is seen as “collecting data about life”. According to Yin (2014: p. 106), the strengths of interviews are that it “focuses directly on the case study topics”, and it is “insightful as it provides explanations as well as personal views (e.g. perceptions, attitudes and meanings)”.

Data collection for this study was done by means of audio-tape recorded, semi-structured interviews with the parents. An interview guide (Addendum F) was used to allow the data collected, to be more comprehensive. The researcher transcribed all the recorded interviews, in order to enhance the confidentiality and privacy of the parents. The maximum time scheduled for each interview was 1 hour 30 minutes. Ten invitations to participate were sent out via the school-based occupational therapist, who recruited the parents with children who have DS. The researcher selected six out of the ten parents, who indicated that they were interested in participating. The parents of the semi-structured interviews included a biological mother and father, a single father, a single mother (father deceased) and a guardian. Two participants did not arrive for the interviews. Interviews were conducted over three days, within one week. The interviews were conducted in the registered counsellor’s room, to ensure the privacy of the parents, as well as confidentiality of any information shared.

3.5.3. Data Analysis

Cohen *et al.* (2011: pp. 427-537) states that qualitative data analysis involves organising and making sense of the data collected from the participants. Nigatu (2009) states that qualitative data analysis is:

“the range of processes and procedures whereby we move from the qualitative data that have been collected into some form of explanation, understanding or interpretation of the people and situations we are investigating. The idea is to examine the meaningful and symbolic content of qualitative data”.

Qualitative data analysis has more of an interpretive nature, which allows data to be more insightful. In this case study, a system of coding and content analysis were used. Content analysis is “a method of data analysis in which content and context are analysed” (Ritchie, Lewis, Nicholls & Ormston, 2014: p. 271). According to Nigatu (2009), content analysis is the technique used to categorise the verbal and non-verbal (observable) data. Its purpose is to organise, classify and summarise the data. Nigatu (2009) states that “the content can be analysed on two levels namely descriptive (what is the data) and interpretative (what was meant by the data)”.

The audio-tape recorded, semi-structured interviews with the parents were considered the raw data collected, and an analysis of each case was made, as well as cross-case analysis, to determine the similarities and differences, and the emerging themes (see Figure 3.2). The findings are discussed in the next chapter. Marshall and Rossman (2011: p. 206) explains how qualitative analysis includes organising the data, theme development and interpretation, as well as report writing. This correlates with Nigatu (2009), who expands on the process of qualitative data analysis, in the following steps:

1. **Organise data:** This includes transcribing and labelling the data.
2. **Identify framework:** This includes identifying the type of framework which can be either an explanatory type as this will be guided by the research questions or an exploratory type of framework as this will be guided by the data. The type of framework will then structure, label and define the data collected. The framework will also be the coding plan.

3. **Sort data in framework:** This involves coding the data and modifying the framework
4. **Use the framework for descriptive analysis:** This includes sorting a range of responses in categories and identifying recurrent themes.
5. **Second order analysis:** This includes identifying recurrent themes, noticing patterns in the data, identifying respondent clusters such as causality and themes, building the sequence of events, to search the data in order to answer research questions and develop a hypothesis or test.

Tashakkori and Teddlie (2010: p. 386) expand on the works of Strauss, who focussed on systematic and reliable coding techniques, which view included quality criteria such as “closeness of the relationship between the codes and categories and relevance which addresses concerns of the participants beyond mere academic interests”. Conducting the data analysis in a single case, as well as cross-case analysis, would add to the dependability and trustworthiness of the research. Figure 3.2 is an illustration of how the data were validated in this current qualitative case study research design.

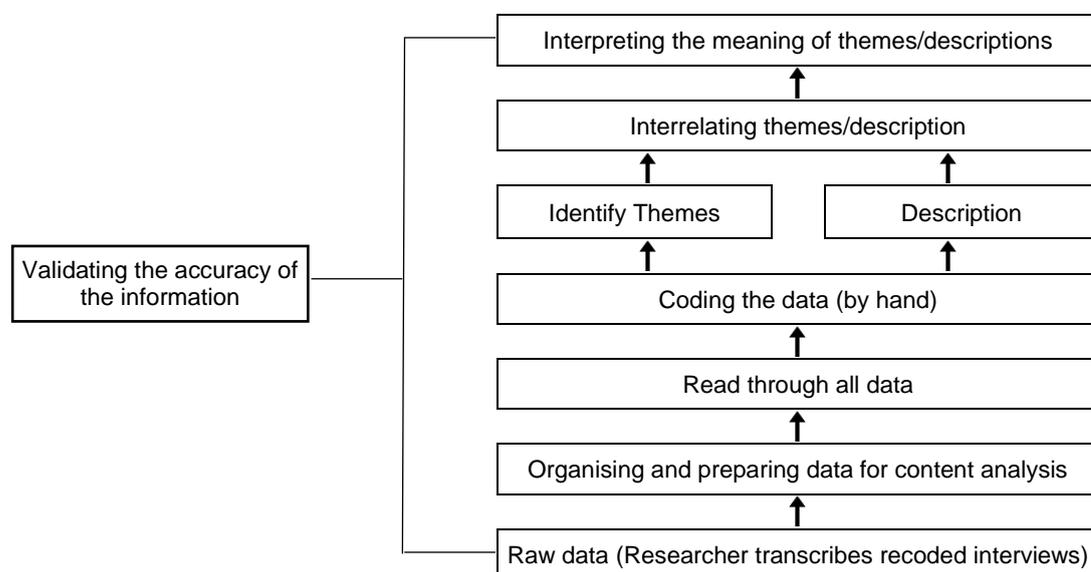


Figure 3.2. Data analysis in qualitative research (Adapted from Creswell, 2009: p. 18)

In this current study, the steps and illustrated diagram for data analysis were as follows:

- All the recorded interviews of the respective participants were labelled and transcribed by the researcher.
- Similar words and phrases were identified, which led to the development of themes emerging from the data.
- These words and phrases were colour coded to establish themes across the different cases.
- Recurring themes were eventually identified and the researcher could establish whether the research questions were answered comprehensively.

The limitations to the study were noted.

3.6. Trustworthiness in Qualitative Research

Denzin and Lincoln (2011: p. 582) state that the “issues of validity in qualitative studies should be linked not to ‘truth’ or ‘value’, as they are for the positivists, but rather to ‘trustworthiness’ which becomes a matter of persuasion whereby the scientist is viewed as having made those practices visible, and therefore auditable.” According to Schwartz-Shea and Yanow (2012: p. 91-114), trustworthiness of a study is measured in terms of validity, reliability, objectivity and generalisation. These key concepts in qualitative design are different, as they cannot be measured in the same way, as a quantitative, or positivist design. The aim of qualitative design is making meaning of individuals’, or an individual’s point of view (their values, beliefs and feelings) within their own context. This means that understanding social phenomena within an interpretive design is “dynamic and fluid”. This would then be inconsistent to the concepts of validity and reliability as known within a positivist research design. Marshall and Rossman (2011: p. 40) allude to “alternative constructs” to validity, reliability, objectivity and generalisability, as being credibility, dependability, confirmability and transferability. Cohen *et al.* (2011: p. 182) describe the constructs validity and reliability within qualitative research as:

- **Validity**

Natural, thick description and high detail on required or important aspects, uniqueness, purposive sample, confirmability, credibility, transferability, dependability and meanings.

- **Reliability**

Dependability, trustworthiness, fidelity to the natural situation and real life, thick description and high detail on required or important aspects, context specificity, honesty and candour, credibility, transferability, applicability and triangulation.

- **Credibility:**

Credibility is considered the most important criterion in creating trustworthiness. Credibility as described by Guba and Lincoln (1981, as cited in Gavin, 2008: p. 55), “involves establishing that the results of qualitative research are credible or believable from the perspective of the participant.” To ensure credibility the researcher has to link the findings with reality so that the truth of the findings can be established (Statistics Solutions, 2017). To ensure credibility in this current study, the participants were purposely selected, as they were able to provide an “insider’s” account of the topic being discussed. Having more than one parent, increased the chances of answering the research questions, as well as validating certain themes that emerged.

- **Dependability**

Dependability is important to trustworthiness because it lays the foundation for the research findings to be “consistent and repeatable”. Dependability is used to authenticate the consistency of the findings in the raw data collected (Statistics Solutions, 2017). To ensure dependability in this current study, the data were collected in the form of audio-tape recorded, face-to-face interviews with the parents, and each case was analysed, as well as cross analysed, with data collected from other parents.

- **Generalizability**

Refers to the ability of extending the validity of one case study’s conclusions to other cases of the same kind (Moriceau, as cited in Mills, Durepos & Wiebe, 2010: p. 2). The researcher has taken all possible steps to ensure the incorporation of the above concepts of trustworthiness.

3.7. Ethical considerations

This current study only commenced once ethical clearance was granted by the respective ethical committees and review boards. Ethical principles and practice are central to the trustworthiness of a study (Marshall & Rossman, 2011: p. 44). Applicable to this current case

study research design, were the ethical agreements, as discussed by Babbie (2011: pp. 478-485) and Marshall and Rossman (2011: pp. 44-48). These included:

1. **Beneficence: do no harm:** The researcher ensured that the participant was protected against any form of psychological harm that could possibly emerge during the study. Although no potential harm was foreseen for the parents, a counselling psychologist engaged for emotional support.
2. **Informed consent:** Participation in the study was voluntary. The purpose, benefits, potential risks, permission to record the interviews, as well as other important aspects of the study, were explained to each participant, and they were asked to sign a consent form (Addendum E). The researcher ensured that each participant understood the informed consent form, while they were allowed to ask questions, in order to clarify any misunderstandings.
3. **Anonymity:** Anonymity in a research guarantees that people reading the study cannot identify a given response to a given participant. The researcher assured the participants that their names, the names of their children, as well as the school, would not be mentioned in the study, and that, should names be needed, pseudonyms would be used. The participants were also assured that no information within the study would be able to identify the families involved.
4. **Confidentiality:** To enhance confidentiality, the researcher assured the participants that no personal information would be made public. In this way, the identity of the participants would be protected. The researcher ensured that all personal information was treated with absolute confidentiality. The data collected were viewed by the researcher and the research supervisor. All data collected were transcribed by the researcher. All documents and data containing personal and confidential information, namely, hardcopies, recordings, etcetera, were locked away in a code protected safe, to which only researcher and research supervisor has access.
5. **Electronic data** was kept on the researcher's password activated laptop, of which only the researcher has the password. The participants signed a consent form stating that the researcher agrees to keep all information confidential (Addendum E). This current study was based on the moral principle of respect for persons, which implies that the researcher would not use the participants in the study, as a means to an end, and that the researcher would respect the individual, their privacy, their anonymity, and their

right to participate, or not. Ethical principles, as discussed above were considered and applied to ensure that the study was of an ethical nature, and that all the participants were treated in an ethical manner.

3.8. Conclusion

In Chapter 3, the researcher explained the research design and methodology, in which this qualitative single-case study research was conducted. The researcher explained the research paradigm, research design, and methodology, which included sampling, data collection and data analysis, as well as the context of the study. The latter part of this chapter included how the research was aligned with the different criteria for trustworthiness in qualitative research. These included validity, reliability, credibility, and generalisation. This study was explorative and unique, as each participant (case) had its own context. The methodology of the study allowed for the data to be comprehensive, as these participants were the experts of their own world. This current study involved data that were of a subjective nature; however, it produced data that were considered general factors, in all the cases.

CHAPTER FOUR

RESEARCH FINDINGS AND DISCUSSION

4.1. Introduction

The aim of this chapter was to discuss the research findings of the study. To put this chapter into perspective, the main aim this study was: to have an in-depth exploration of the perspectives and experiences of parents, living in low socio-economic areas within Cape Town, in meeting the developmental care needs of their child with DS. This chapter thus presents the research context, findings and discussion of the study.

4.2. Context of the research

The particular school in this study is situated in a middle-income area, but the overall majority of the parents attached to the school, live in low socio-economic areas. Most of the learners are bussed to school from many different areas including Blikkiesdorp, Delft, Elsies River, Bishop Lavis, Bonteheuwel, Joe Slovo Park, Bridgetown, and Kensington. These areas are known for poor housing, over-crowded homes, high unemployment rates and gangsterism. According to Crime Stats SA (2015), these areas are considered high crime areas. Most of these areas are marked as red zone areas in Cape Town, where paramedics need police assistance to go into the area.

4.2.1. The participants

This research was approached from the theoretical lens presented by Bronfenbrenner's bio-ecological model that helps us to understand the contextual influences on child development and care. This model presents different systems that impact on the development of the individual. It is therefore important that the contextual factors impacting on parenting a child with DS be considered. The *Names** have been changed to protect the identity of the participants and schools. The participants in this study included a mother as legal guardian, biological single mother, a biological father and biological mother and father. The children to the above parents were between the ages of 10 and 16 years old.

4.2.1.1. *Mrs James* (P1)*

Mrs James is the legal guardian to *Adrian** since the age of two months. She is considered to be a go-between-mother as she fosters babies for the first few months before they are adopted. When she was approached by the welfare organisation to look after a “disabled child”, she instinctively knew that she “can’t pass him on”. *Adrian* is currently one of five children living with *Mrs James*. It was very apparent throughout the interview that *Mrs James* is a very compassionate mother and she is very involved in *Adrian*’s educational journey. A few years ago, *Mrs James* lost her husband in a car accident and she has been a single mother since then. She lives in *Elsies River* which is one of the communities described above. *Mrs James* lived with her mother for many years while she and her husband tried to build their own house. After the death of her husband, her family decided to help her complete the building of her house. She now lives happily on her own. This has been a major accomplishment for *Mrs James* as she spoke about it with so much joy and happiness. *Adrian* is a child who had many health issues such as difficulty with his bladder, thyroid, chest, eczema and difficulty with speech. Due to these health issues, *Mrs James* had to attend many hospitals over the years. *Mrs James* was not given much information regarding Down syndrome when *Adrian* came home from the foster institute. It was only once she started attending the support group, that she was educated on Down syndrome. *Adrian* attends a public special school which is not far from where they live but he still requires transport to get to school. After two years at the *Elsies River Special School*, *Mrs James* felt that *Adrian* was not making significant academic progress and withdrew him from the school without notifying the teacher or principal. She enrolled *Adrian* at *Roudale Primary School* which is a full service school that could accommodate him in their unit class. *Mrs James* was hopeful that *Adrian* could learn more at this school. Although the new school was far from their home, *Mrs James* did not seem to mind the financial costs incurred as she wanted the best education for her child. After *Adrian* was there for six months, the school informed *Mrs James* that they were not able to cope with *Adrian*’s high educational needs and that it would be best for her to take him back to his previous school. *Mrs James* expressed her deep disappointment but took *Adrian* back to his *Elsies River Special School*. With the help of the principal at *Roudale Primary School*, *Adrian* was allowed back. As the interview progressed, I

could understand why Mrs *James* saw the need to move *Adrian* to another school.

She firmly believed that children with disabilities should not be placed in one particular school as they need typical developing children to be role models to children with disabilities. At one point during the interview there was a strong sense that she treated *Adrian* as a “normal child” and that she would want others to treat him that way too. I respect her views and fully understand this. She suffered many setbacks and challenges within the family, community and the education system. Resources and professional services were not easily accessible and available in the community. The only support in the community was the social worker who was part of the support group at the hospital. *Mrs James* is quite proud of herself that she has learnt so much about Down Syndrome over the years that she feels she is now able to assist other parents. What stood out for me throughout the interview was her resilience, perseverance and acceptance of her situation and circumstances. She did not complain much but rather expressed her desire to educate herself in any way possible in order for her to assist her child with Down syndrome.

4.2.1.2. *Mrs Hammond** (P2)

Mrs Hammond is a single, biological mother to *Mishca**. *Mrs Hammond's* husband passed on many years ago. She has two children of whom *Mishca* is the youngest. *Mrs Hammond* seemed to be a gentle, soft-spoken lady. She speaks very fondly of *Mishca*. This family lives in a separate entrance on someone's property in Elsie's River which is one of the communities mentioned above. *Mrs Hammond* had to give up her job after *Mishca* was born in order to look after her. This, according to her, added to their financial predicament but she had no choice. It became apparent throughout the interview that financial stressors were huge for this family despite the government grant received for *Mishca*. It appeared that *Mrs Hammond* lacked physical as well as emotional support from family and friends. She mentioned that she often did not have someone to speak to and that she felt lonely. She proudly spoke of how *Mishca* would ask her about the knitting she does and sells as an income for the family. She reported that whenever *Mishca* got sick, she did not have anyone to take her to the hospital. She would then try to nurse the child through the night and wait till morning to take the taxi to the day hospital. She often did not even have taxi fare to go to hospital. The lack of support was a major

negative factor that stood out for me. The safety of her child was her main concern. She would not allow her child to play outside or interact with people in the community as she feared her child would be abused or kidnapped. This seems to have been a common fear amongst the parents. *Mishca* was born at Bonteheuwel Day hospital. Two days later she developed yellow jaundice. Her mother took her back to the hospital where she was born and *Mishca* was rushed from there to Somerset Hospital. *Mrs Hammond* very sadly told me how she was not allowed to stay with her child at the hospital. She went home to look after her older son who was at the grandmother's place till *Mrs Hammond* returned home. After two days she went back to the hospital and it was only then that the doctor informed her that her child has Down syndrome. According to *Mrs Hammond* he said that it is not easy to raise a child with Down syndrome as they have many health issues. Later the doctors discovered that *Mishca* had a heart murmur. After many hospital visits *Mishca*, at the age of seven months, had corrective heart surgery. When *Mishca* was older, she developed cellulitis. This was a difficult period for *Mrs Hammond*. She appeared to be emotional when she mentioned that the nurse at the day hospital asked her to complete a form. Upon inquiring what the form was about, the nurse told her that it's a form requesting placement for her child at a children's home as it is very difficult to have a child with Down syndrome and these health issues. *Mrs Hammond* expressed her disappointment in the nurse. It appeared that this incident had a major traumatic impact on *Mrs Hammond*. *Mrs Hammond* was referred to Red Cross hospital where she attended the toy Library parent sessions. This was a great support in the initial stages of *Mishca's* life. It was through the toy library that *Mrs Hammond* was referred to *Bellville Special School*. Although, it was far from their home, *Mrs Hammond* was happy that her child could attend school. As *Mishca* started school, the financial challenges increased for the family. This also placed strain on the parents' relationship. It was after a year at the school, that educators and the principal assisted and supported *Mrs Hammond* in getting a transfer for *Mishca* to *Elsies River Special School*. It seems that *Mrs Hammond* was well supported in terms of *Mishca's* educational needs. *Mrs Hammond* reported that she is very happy with *Mishca's* progress at the school. *Mishca* is learning to be independent. It was apparent that although *Mrs Hammond* had many challenges, she persevered and drew on her faith throughout this tough journey of raising her child with DownsSyndrome. *Mrs Hammond* was surely a parent who

needed lots of support and resources from professionals, NOG's and people in the community. It was clear that there is a lack of resources and services available to her in the community where she lives. When asked what advice she would give to parents who have children with Down syndrome, she immediately replied that parents have to love their children, not give them away and trust God to carry them through. It was clear that *Mrs Hammond* has a fighting spirit even though she had a timid and frail physique.

4.2.1.3. *Mr Andile* (P3)*

Mr Andile is the biological father of *Suzy**. Due to circumstances his wife could not attend the scheduled and rescheduled interview. *Mr Andile* works as a driver, at *Elsies River Special School* and lives in a small flat in Joe Slovo Park near Milnerton. This is one of the communities described above. His wife works at a school close to their home. He has three children of which two are grown adults and *Suzy* is the youngest. *Mr Andile* seems a very dedicated father to *Suzy*. Throughout the interview, he spoke very fondly of her. He mentioned that he loves the attention she gets when they go to the mall. It was very apparent that *Mr Andile* is a very hands on father to *Suzy*. It was clear that *Mr Andile* is the head of the family and (as within their culture) his opinion regarding many aspects, is significant when it comes to decisions. He very proudly stated that he provides for his family even if they get a government grant for *Suzy*. *Suzy* was born at Bonteheuwel Day Hospital where the doctor told *Mrs Andile* that their child has Down syndrome. The doctor did not explain what Down syndrome is all about. *Mr Andile* reported that his wife came home very upset and gave him the news. His initial response was that he did not take this to be serious. According to him, it is not within their culture to know much about Down syndrome or other disabilities. He mentioned that he started noticing *Suzy*'s flat nose and thought that maybe this is true. *Suzy* was very sick in the beginning and they discovered that she had chest problems and a hole in her heart. She was diagnosed with Asthma. Upon many visits to Red Cross Hospital and rescheduled operations, they discovered that *Suzy*'s heart condition had improved and that the hole had closed by itself. *Suzy* also has a speech impediment. *Mr Andile* and his wife attended the toy library at Red Cross where they learnt more about Down syndrome. It was reported that there were no resources and support services in their community for parents who had

children with Down Syndrome. *Mr Andile* mentioned though that he encouraged *Suzy* to play with the children in their community. He mentioned that his wife was concerned that children would be nasty to *Suzy* but he said the more they see her the more they will get use to her. *Suzy* apparently, now plays with all the children in their block of flats and gets along well with all of them. *Suzy* attended a crèche in the community. They accepted *Suzy* without prejudice. *Suzy* started grade R at the school where her mother is currently working. According to *Mr Andile*, this was a good environment for *Suzy* as she played with other children and she could learn from them. It was however, not a good experience for *Mrs Andile* as *Suzy* was in her class and would often run out of class. This placed *Mrs Andile* under lots of pressure. After a few months at the school the principal assisted the family to get *Suzy* enrolled at *Elsies River Special School*. Although this is quite a distance from their home in Joe Slovo, it was the nearest special school. This was also made possible after *Mr Andile* got a permanent appointment as driver at the school. *Mr Andile* seemed very impressed with the school. He mentioned that he could always go to the school sister (nurse) if he wants to know how to handle *Suzy*. *Suzy*'s safety was also a major concern for him. As a father he was concerned about his daughter being sexually abused, contracting HIV and other sexually transmitted diseases. He was well educated by the school regarding legal matters and operations for *Suzy*. The school was a good support network for *Mr Andile* and his family.

4.2.1.4. *Mr and Mrs Davids**

Mr and Mrs Davids (P4 & P5) are the biological parents of *Yaasien**. They have three boys of whom *Yaasien** is the youngest. *Mr And Mrs Davids* lived in a granny flat with *Mrs Davids*' family for many years until they could afford to be on their own. They currently live in their own home in Delft which is one of the communities mentioned above. Throughout the interview, it was clear that *Mr and Mrs Davids* are very involved in *Yaasien*'s life. *Mr and Mrs Davids* were informed during one of the pregnancy consultations that there might be a one percent chance that their baby might be Down syndrome. According to *Mr Davids* (P4) he did not take note of this as it was only a one percent chance. At the birth of their child they were not informed that their child had Down syndrome. *Mr Davids* reported that he picked it up immediately but he did not say anything to his wife. His wife did not suspect anything. It was only when *Yaasien* developed yellow jaundice two

weeks later that they were informed about his diagnosis. *Mrs Davids* (P5) conveyed how she felt like a zombie when she heard that their child has Down syndrome. She mentioned that when she got home, she burst into tears as she could not accept that this was happening. When she mentioned to *Mr Davids* what the doctor had said, he admitted that he knew but he did not want her to feel upset. It was clear that he cared for his wife and wanted to protect her from the hurt of hearing this diagnosis. He embraced it and encouraged his wife to do the same. *Mrs Davids* admits that it was fear of the unknown diagnosis that caused her to panic and have anxiety. They accepted *Yaasien* and moved on. *Yaasien* had to undergo many tests to determine his state of health. At first they thought he had difficulty hearing and might have a heart condition but both of these proved to be negative. He does have a problem with his chest though. *Mr and Mrs Davids* seem to have a good support network with their family and friends. There are not many resources and support services in their community though but *Yaasien* has been doing karate in the community. His parents were very proud when they mentioned that he is well accepted by the karate master and the children. It became very apparent that the major challenge for these parents were the bedtime routine. *Yaasien* apparently, does not sleep well throughout the night and both parents but more so *Mrs Davids* (as she is unemployed), has to get up several times during the night to comfort *Yaasien*. *Mr and Mrs Davids* report this to be a very tiring exercise. One of their major fears includes care for *Yaasien* if they should pass on. This is also a common fear amongst the parents interviewed. *Mrs Davids* became emotional at times when she spoke about how she tried her best to protect *Yaasien* from children and adults being nasty to him when he was younger. *Mr and Mrs Davids* were parents who were very involved in *Yaasien*'s education and it was clear that they want the best for their child. Both parents reported that *Yaasien* added value to their lives. They also mentioned the importance of God and faith in raising a child with Down syndrome.

4.3. DATA ANALYSIS AND DISCUSSION

The findings (content and context) from the semi-structured interviews were analysed according to the content analysis method as described by Nigatu (2009). This section presents the similarities of the participants' experiences. The data collected is then presented and

discussed according to the themes and sub-themes that emerged.

Table 4.1: Similarities between the participants

Similarities	Participants			
	P1	P2	P3	P4 & P5
Religion	X	X	X	X
Children's health issues due to diagnosis	X	X	X	X
Acceptance of their child's diagnosis	X	X	X	X
Extended Family support	X		X	X
Socio-economic area	X	X	X	X
Lack of resources and support structures in community	X	X	X	X
Emotional Challenges	X	X	X	X
Medical/social Support	X	X	X	X
Perseverance	X	X	X	X
Fear of child's safety	X	X	X	X
Concern about the child after parents die	X	X	X	X
Advice to parents: accept and love your child	X	X	X	X
Deep love for their child	X	X	X	X
Financial stress	X	X	X	X
Educational/school support		X	X	X
Make use of public hospitals	X	X	X	X

Although these parents (P1-P5) have different family backgrounds, Table 4.1 indicates that there were many similarities between the participants' experiences. These similarities included, amongst other, their children's' health issues, beliefs, emotional challenges such as fear, anxiety, constant worry as well as financial stressors. Most parents had support from their extended families with the exception of P2. All the parents seemed to have had some support from the schools except for P1. The following categories emerged from the data collected.

Table 4.2: Categories as they emerged from the data

Categories	Raw data (1 example only)	Participants
	The responses below are verbatim and have not been edited.	
Medical related issues	<p>“He had a thyroid problem.”</p> <p>“<i>Mishca</i>* had a murmur on the heart”</p> <p>“she had a hole in her heart”</p> <p>“they found ... I think after two days, yellow jaundice”</p>	<p><i>Mrs James</i></p> <p><i>Mrs Hammond</i></p> <p><i>Mr Andile</i></p> <p><i>Mr & Mrs Davids</i></p>
Support	<p>“they helped me handle the child”</p> <p>“the nurse always used to help”</p> <p>“let me go to sister and ask what is going to happen now”</p> <p>“we had a lot of help”</p>	<p><i>Mrs James</i></p> <p><i>Mrs Hammond</i></p> <p><i>Mr Andile</i></p> <p><i>Mr & Mrs Davids</i></p>
Emotional experiences	<p>“so I pop in to check if he’s breathing because I was very scared”</p> <p>“I felt very emotional”</p> <p>“Yeah, because that one is a little bit worrying, if I die”</p> <p>“I just burst out crying (looking emotional)”</p> <p>“When he was born ... uhm you know ... I picked it up immediately, but I kept it to myself”</p>	<p><i>Mrs James</i></p> <p><i>Mrs Hammond</i></p> <p><i>Mr Andile</i></p> <p><i>Mr Davids</i></p> <p><i>Mr Davids</i></p>
Religion/Faith and Culture	<p>“because God made us normal, never mind the disability”</p> <p>“I wasn’t so close to God the way I am now”</p> <p>“I thought it was God saying she must not have the operation”</p> <p>“This is what God has given us and we must accept it. It is our child”</p>	<p><i>Mrs James</i></p> <p><i>Mrs Hammond</i></p> <p><i>Mr Andile</i></p> <p><i>Mr Davids</i></p>
Challenges	<p>“bring him to the school to ask for a speech therapist but then nothing happen”</p> <p>“sometimes one parent had to be at the hospital with her and the one had to go home to see to the other one. And it wasn’t easy”</p> <p>“What I’ve noticed is that white people are used to this thing (Down Syndrome), black people they are not”</p> <p>“Yes ... I would put him to bed at eight o’ clock and he would call me till he falls asleep. Mommy ... hug me ... now I go back ... knowing he is gonna call again”</p>	<p><i>Mrs James</i></p> <p><i>Mrs Hammond</i></p> <p><i>Mr Andile</i></p> <p><i>Mr & Mrs Davids</i></p>
Positive experiences	<p>“I’m through the potty training but, I can give other people advice”</p> <p>“there are times where I feel like giving up on this, but she just give me that spirit just to carry on again”</p> <p>“people will give that attention also. So, you see, so I like that”</p> <p>“I think it actually made our family. My brothers, my sisters, we all came more closer”</p>	<p><i>Mrs James</i></p> <p><i>Mrs Hammond</i></p> <p><i>Mr Andile</i></p> <p><i>Mr & Mrs Davids</i></p>

Although the stories unfolded very differently for each parent, the data suggested similar experiences, perspectives and challenges that were categorised in Table 4.2. Many of the parents experienced extensive hospital visits due to their child's medical condition related to the diagnosis of Down Syndrome. The parents stem from different religious and cultural backgrounds, and it was very apparent throughout the interviews that faith is important. The diagnosis of their child had a significant negative as well as positive impact on their lives. The above categories have been combined into the following themes and sub-themes:

Table 4.3: Themes and sub-themes

Main themes	Sub-themes
1. The perspectives and experiences of the parents on raising their child with Down Syndrome	Experiences regarding: <ul style="list-style-type: none"> the initial diagnosis, and the health issues of their child. meeting their child's physical, educational, social and emotional needs. The overall emotional experiences.
2. The challenges faced by parents	<ul style="list-style-type: none"> Socio-economic area: Resources, support services and community. Personal challenges/ relationships/parenting styles
3. Resilience as experienced by the parents	<ul style="list-style-type: none"> Acceptance / faith /religion/culture

The different categories have been merged into three themes, each with its own sub- themes as presented in Table 4.3. These themes include the parents' overall experiences and perspectives on raising their child with Down syndrome, their challenges and the resilience they have experienced over the years. The findings will now be discussed according the themes identified in Table 4.3.

4.3.1. Main theme 1: The perspectives and experiences of the parents on raising their child with Down syndrome

4.3.1.1. Sub-theme: *Experiences regarding the initial diagnosis, and the health issues of their child*

Most of the parents had a shocking introduction to their child's diagnosis. *Mrs James* had this reaction upon hearing that *Adrian* has Down Syndrome:

"I thought what is it? Is it just people that drink?"

These parents were not told what the diagnosis was, until weeks after the birth of their child and until health related issues started and parents had to make sacrifices (amidst their dire financial situation) to get the child to hospital. This was the experience of *Mrs Hammond*:

“after she was born, two days later, she developed yellow jaundice. Mishca was rushed back to hospital (Bonteheuwel Day hospital). She was rushed from there to Somerset hospital. ... You were not allowed to stay there, you could just visit. ... every second week we were sitting at Red Cross Hospital”.

The two fathers involved seemed to have ignored the news of the diagnosis as they thought the nurses or doctors might be wrong or perhaps it could have been denial of the situation. *Mr Andile*'s initial response upon hearing his daughter had Down Syndrome was the following:

“... didn't take it serious” and then: “things were really difficult for me, you see the first time hearing it. It's my child this”. Mr Davids on the other hand suspected that something was wrong as he verbalised himself: “When he was born ... uhm you know ... I picked it up immediately, but I kept it to myself.”

For many of the mothers it was sad hearing that their new baby has Down Syndrome. They experienced fear and much anxiety. Medical and health conditions of the different children included asthma, yellow jaundice, a murmur on the heart, a hole in the heart (medical term: ASD-atrial septal defect), thyroid problems, bladder problems, speech difficulties, eczema, cellulitis and diarrhoea. The parents experienced many hospital visits soon after the birth of their child. Many of them visited more than just one hospital as some hospital were not equipped to help them. These constant hospital visits had financial implications, emotional impact on some of the parents and added strain to some relationships. The following is how *Mrs Davids* expressed her experiences:

“I was like a zombie. I just listened and didn't say anything. When I got to the car ... and I just burst our crying (emotional).”

“sleeping in the hospitals ... we had to spend time with him in the hospitals. I would take the night shift and she would take the day shift ... and it actually got to the point where we became so tired.”

4.3.1.2. Sub-theme: Experiences regarding physical, educational, social and emotional needs of the child

Some parents admitted that it was very stressful trying to meet the social demands of their child. Whether the child was with family, friends or interacting with people in the community, safety was always an issue. Some parents felt it is best to keep the child away from people and children as some people acted in a nasty manner towards the child. *Mrs Hammond's* concern was:

“she is a very friendly child ... but you know there are people that will steal you (referring to the child)”.

Although *Mr Andile* also had concerns for his child's safety, he had a very different approach to the social interaction of his child with other children or people. He said the following:

“children will see she is different, her face you see ... She must not stay indoors. She must go play with them”.

Most parents indicated that they removed their children from a situation where their children seemed under emotional stress. Parents had to pay more attention to their child with Down Syndrome than their other children as their emotional and other needs were different. *Mr Andile* said:

“she's the one that needs to be taken care of. She needs more attention than the other one”.

Mr and Mrs Davids reported that they always try to keep their son happy by giving him what he wants otherwise he will not stop nagging. This was their response:

“I told her, let's go buy him a toy. He is always crying for a new toy”.

Of the parents also reported that the physical demands on them as parents impacted on their relationship and how they approached their child. The developmental

delays of the children required parents to be patient and to help their children well beyond the toddler stages. This is what *Mr Andile* had to say about his daughter *Suzy*'s physical milestones:

“it took her long, it took her two years to walk”.

Toileting and bed routines were a common problem for most parents. It was clear that *Mrs Hammond* was not informed of the delay in some of the milestones for children with Down Syndrome. She indicated the following:

“when Mishca was two years old, she was still on the nappy... there were children that were already wearing panty. I asked the hospital ... but why this?”

Mr and Mrs Davids' child was quite a big boy. It was evident that these parents were proactive in trying to meet every need, especially his physical needs, since birth. The following is what *Mr Davids* did for his son when he was still a baby:

“I made his cot a certain way for him to grow ... with lots of holes in that area. So you know, he can start pulling himself up”.

They also implemented the physical exercises for their child as it was shown to them at the toy library: *“they will show us exercises we must do (with the child)”*. *Mr Andile* also mentioned that it took his daughter a while before she could walk.

Meeting the educational demands also seemed challenging to some parents. It was quite evident that *Mrs James* had high academic aspirations for her son despite him having Down Syndrome. She felt that her son's educational needs were not quite met at the different schools. She had a strong belief that children with disabilities should be in a mainstream school with other typically developing children as children with Down Syndrome could pick up social cues and behaviour from typically developing children. She expressed herself as follows:

“I thought he was not making progress here (special school), so I took him out (of my own), so I put him in a school (mainstream school) by us, and there he was for a year before they called me in to say they

can't cope".

"I feel, don't put all the children with disability in one school like this."

Despite the complex and constant demands on these parents to meet the needs of their children, it was evident that each of the parents did their best to support their child. This demonstrates the resilience that parents have built up over the years.

4.3.1.3. Sub-theme: The overall emotional experiences

The overall emotional experiences of the parents included emotions such as being shocked, fear, anxiety, disappointment, denial, rejection, lack of support, acceptance and happiness. For some of the parents the emotional journey started before the birth of their child. *Mr Davids* mentioned what the doctor told them when his wife went for her first scan at Groote Schuur hospital: “

she told us that uhm, there is a one percent chance that he will be Down Syndrome. She actually said that ninety nine percent she is going to say that it is not, but she cannot say he's not Down Syndrome and then he is".

Of the parents reported having closer family relations, having more and better knowledge of Down Syndrome and feeling proud that they are now able to help other parents. *Mrs Hammond* felt that her experience with her daughter *Mishca* brought about a change in her relationship with her son:

"it brought us much closer". Mrs Davids responded: "I think it actually made our family, my brothers, my sisters and my parents ... we all became more closer. I had a lot of help".

Although, most parents reported that they would not change their lives because of their child, they also admitted that it has not been an easy road. They have experienced much pain and had to endure many hardships, but they also reported that their lives were enriched in some way. *Mrs Hammond* experienced much pain, loneliness and stress. Throughout the interviews it was very apparent that she has had quiet an emotional journey. These were her words:

"I was just standing in the passage crying". "I have learned to accept

it. It's not easy. There are times when I do feel frustrated. I do feel lonely. Then I tell myself -must I go through this all alone”.

Mrs Davids expressed how she felt managing her son after he was born:

“It was really stressful”.

Mr Davids felt that he was a tough guy before his son came along. He feels that his son has caused him to approach things a bit differently:

“I was a very, very stubborn guy. It was my way is the high way ... it made me soft. I can't say no to him”.

Mr Andile who came from a very different cultural background had a change in his attitude and heart towards his daughter. He felt:

“what I've noticed is that white people are used to this thing (Down Syndrome), black people they are not. We are not taught about this thing. We don't have gatherings where we teach about (Down Syndrome)”. “It changed me because I love her more than the other one. She's the one that needs to be taken care of.”

Many of the parents wanted to protect their children from emotional rejection. This was *Mr Davids*' response to protecting his son from emotional distress when he sees people staring at his son:

“you see people stare ... It breaks his (son) spirit. It doesn't make him feel “lekker” (comfortable) ... I put a smile on my face and will give him a kiss and a hug”. “We also feel the distress. ... we also like ... sad man.”

Some of the parents did not experience much or any support from the extended family. *Mrs Hammond*, as a single parent, seemingly had quite a tough time and responded:

“and family wasn't so ... they weren't so interested”.

Parents reported that some family members did not accept their child at first or they

were scared of the treatment their child would receive from family and people around them. *Mrs James* was visibly very emotional when she shared the following:

“Family did not accept him at once”. Mrs Davids expressed her fears just thinking that her son would be ill-treated by people. Her words were: “I think my fear was ... how was people going to treat him.”

Most parents were concerned about the safety of their children in their communities and society as child trafficking is trending in Cape Town at the moment. *Mrs James* had this to say regarding her child interacting with other people in their community:

“I don’t want him to get comfortable with the people. People are so weird, they can do anything with the children and I’m just scared, I’m just scared.”

Mr Davids had the following response when asked about the social interaction of his child in their community:

“it’s the crime. He’s not allowed to play outside. We enclosed our property completely. If he needs to go outside, it will be till the gate. He know don’t go outside because of the crime ... people behind us were murderers”.

It was clear that *Mr and Mrs Davids* were not prepared to risk their son’s safety or emotional well-being. Although they expressed that it was not always easy to have him with them at all times, they would not leave him with anyone except his grandparents. This is what they had to say:

“it’s not about not allowing him to be with the family. It’s not being there if anything goes wrong. That’s our fear.”

One of the main concerns the parents had, was who would be responsible for their child after they pass on. However, not one of the parents discussed this very sensitive and emotional topic with their family members. *Mr Andile* expressed his worry and fears as follows:

“I’m worried, I’m worried if I die ... other family members. How are they gonna take care of her?” ... “who is going to look after her when I pass away.” “I haven’t discussed with the family (what should happen if I die)”.

Mr Davids shared the same concern in saying:

“I haven’t discussed this with the family”.

Mrs Hammond does not have many family members to depend on. Her response was:

“My fears are that if something happens to me, where, what is going to happen to Mishca, that’s my fear. There is no family really”.

Throughout the interviews it was evident that marital and family relationships took strain at some point. With both biological sets of parents, it appeared that their parenting styles were different. The fathers seemingly dealt with matters very differently than the mothers. *Mr Andile* and his wife clearly had different ways as to how they approached their child in terms of social interaction. He said the following:

“I was okay, I told her (his wife) leave her, she (Suzy) must be with others”.

Mr and Mrs Davids also seemed to have approached discipline differently at some point. He said:

“I always tell her. Her belief is, if there is a problem, sort it out. Don’t expect me to come home and “slaan die laaitie nou” (hit the boy now).

Bedtime with their son was challenging for this couple. *Mrs Davids* expressed the following

“I stand up whenever he calls me ... he (her husband) won’t. It can be what time during the night. I will stand up and go hug him.”

Mr Davids’ response to bedtime routine was:

“I can’t afford ... disturbing my rest like that. I need to be wide awake at work. I every time tell her - “jy het te veel pity” (you have too much pity).

The lack of financial support for some parents, led to many emotional experiences such as disappointment and hopelessness. Although all parents now receive government grants for their children, it was not an easy process to get grants. Parents were not adequately informed as to where to go or that they could get grants for their child. Based on parents’ reports, medical professionals did not give them adequate information regarding accessing of grants for their children. In fact, one parent reported that the doctor said his child will be able to look after himself when he is grown. The lack of support in this regard and other aspects was also experienced within their communities. *Mrs Hammond* experienced the following:

“Mishca was born. I hadn’t worked since then. So my husband was working and the place where he was working, it closed down. So, it wasn’t easy, he was also out of work”. “You can’t say doctors must do it, but financially we do need a bit more support”. Mr and Mrs Davids approached the hospital for financial advice and support: “they declined us there by the hospital ... I asked the doctor why don’t you want to help us? The doctor said:” he (Yaasien) is able to look after himself one day”. You know, that was a setback to me because this is a doctor. How can you not help him (son)?” (silence) “It will make our lives a bit easier”.

Many of the parents reportedly, had good support from the schools they were connected to. *Mr Andile*’s response to the crèche where *Suzy* attended as a toddler was:

“I know the crèche, I was taking her to, they liked her very much ... and also the children”.

His response to the current school is very positive as his daughter has learnt so much:

“now she (Suzy) can see her name and she can say ‘daddy this is my name “Suzy”.

Mrs Hammond had a pleasant experience at both of the schools her daughter attended. This is what she had to say about the current school:

“Yes, I have learnt a lot at Elsie’s River Special School”.

Mr and Mrs Davids felt the school could have supported them as parents a bit more

“we didn’t get support like that from them”

but they have indicated that the teachers treated the children well:

“I think the way they (the teachers) treat the children ... to us that was flying”.

Mrs James however, felt that she did not have such a pleasant experience in terms of the support from the schools that her son attended and was visibly upset when she spoke about it.

Through all of these experiences, parents generally felt that they are in a better position to assist other parents who are going through similar circumstances. The parents felt confident enough to share their experiences and to advise parents, teachers and professionals on how they could make changes that would benefit other parents who have children with Down Syndrome. *Mrs James* felt very confident that she is now able to assist other parents. She said the following:

“because I learn a lot how to handle him” ... I can give other people advice”.

4.3.2. Main theme 2: The challenges faced by parents

4.3.2.1. Sub-theme: Socio-economic area: Resources, Support services and community

All the parents interviewed live in low socio-economic areas. These areas, as discussed above, are well known for their crime related activities, over-crowded housing and gang-related incidents. *Mrs Hammond* was not raised by her own mother. She was raised by a lady who was a domestic worker in the Kensington area:

“that time I lived in Kensington ... we moved to Elsie when Mishca was two years old”.

Mr and Mrs Davids were not living in their own home when their son was born:

“we use to live in Surrey Estate when he was born ... he (Yaasien) was three years old when we moved to Delft”.

Most of the mothers gave birth outside of their own communities as each of these areas has a designated day hospital. As with these state facilities, mothers are discharged the same day after birth. This type of environment can cause lots of emotional stress to any parent. All the parents used state hospitals. *Mrs Hammond* lived in Kensington and gave birth in Bonteheuwel:

“we took her back to the hospital where she was born, that was in Bonteheuwel, the day hospital”.

Mrs Hammond had to travel between the following state hospitals: Bonteheuwel Day Hospital, Somerset Hospital, Goodwood Day Hospital and Red Cross Hospital to attend to her daughter’s medical conditions. *Mr and Mrs Davids* attended the following state hospitals: Groote Schuur hospital, Hanover Park Clinic, Somerset Hospital and Red Cross Hospital to attend to Yaasien’s health during the initial stages of his life. *Mrs Davids* had her first scan at Groote Schuur hospital. *Mr Andile* lives in a township close to Millerton but this is his comment about where his child was born:

“she (Suzy) was born in Bonteheuwel (day hospital)”.

According to *Mr Andile’s* report, they attended state hospitals such as Bonteheuwel Day Hospital and Red Cross Hospital. *Mrs James’* adopted son was born at Karl Bremer Hospital and soon after birth he was sent to Tygerberg Hospital.

Not all parents were fortunate enough to have their own homes and not all of them are employed. *Mrs Hammond* is a single, unemployed mother and shares a property with another family:

“we have been living on this property since she (Mishca) was two years

old and she is now sixteen”.

She lives in a separate entrance with her children.

Mr and Mrs Davids lived with Mrs Davids’ mother at first until they could afford their own home in Delft:

“at that time we lived in a granny flat at the back by my mommy ... he was three years old when we moved to Delft”.

Mr Andile is originally from the Eastern Cape. He mentions that he has his own home over there but here in Cape Town:

“I don’t have a house. I have one room you see. I need the house for this (child with Down Syndrome)”.

Mrs James also shared a home with family at first while she and her husband were trying to complete the building of their house. Unfortunately, Mrs James’ husband passed away before they completed their house. Her family was kind enough to support her in this regard. This was her response to where she lived

“we were staying with my mother ... after my husband died ... my family helped me build finish my house”.

The above mentioned socio-economic areas are not well equipped with resources or support services to assist parents who have typically developing children and even less equipped for children with disabilities. Mrs James’ experience was

“there’s nothing for us ... we can’t go to a speech therapist. If there was more support, you know, people to help us”.

Mrs Hammond did not have to feel the lack of support:

“nobody to take me to the day hospital or Red Cross”

if her community had the necessary medical support services. Mr Andile also experienced lack of medical support and other resources. He mentioned that

“it was only Red Cross. They take care of her”.

Mr and Mrs Davids experienced having to drive from the one hospital (nearest to them), to the other to get the necessary medical assistance when their child had yellow jaundice:

“It was up and down from Hanover Park Clinic to Somerset Hospital.”

Many of the parents living in these communities do not have the financial resources to access private medical or other professional services. Many of the parents had financial stressors as they needed to access hospitals outside of their community to attend to their child’s medical needs. One of the parents felt that life would have been easier for her if there were resources or support services such as counselling or any assistance for her child. For most parents it was a financial sacrifice to access support groups or support services.

It was quite sad to realise that parents were afraid to let their children play outside or walk around in the community as it was not safe. Most parents also felt that children in their area were not friendly towards their child. Mrs James was visibly disturbed when she mentioned:

“we got a school opposite us, but the children make fun of him

... then they (her son and daughter) have to go to the corner to get the (school) bus”.

Mrs Hammond had a similar experience in her community regarding her child:

“even in the community, up till today, they don’t worry with her. She doesn’t go and play with friends in the community ... they do greet and things like that, but I don’t trust children with Mishca. Children can be funny with her at times ... even grownups.”

Parents felt the need to educate adults and children about their child first before they could interact. This caused parents to rather withdraw from people in the community. Most of them would only allow the child to interact with the neighbour. *Mr Andile* felt that the children in the community will just have to get use to his daughter and the way she looks. He encouraged her to play outside with other

children. This was his comment regarding the children in his community:

*“go and learn, go play with others, so that they can get use to her.
That’s what we did.”*

There were some happy moments experienced in the community though. *Mr Davids* mentioned that in his community they offered karate classes. This is what he did:

“we enrolled him in karate class ... it’s the only thing that’s there for him in the community”.

His son was accepted at this club and the karate leader and children are very supportive. There are no schools in these areas that can accommodate the children with Down Syndrome. This means that parents have to pay for transport to get their child to a special school outside of the community. This places the parents under even more financial stress.

4.3.2.2 Sub-theme: Personal challenges/ relationships/parenting styles

Based on my observation throughout the interviews, it was obvious that parents approached their child differently when it came to certain aspects. Some parents whether married or not, had more personal challenges than others. One of the parents desperately wanted people to treat (and possibly see) her child as normal. This particular parent would often emphasise that she saw her child as “normal”. She used the word “normal” more than any of the other parents. It was my observation that she seemed to use this as a coping mechanism. These were her comments:

“I took him as a normal child ... he grew up with all the other normal children ... we brought him up like a normal child ... he got like a normal child off the nappy ... he was at a normal crèche ... with all the normal children.”

It was evident that parenting styles were different and at some point it impacted on parents’ relationship. However, most parents agreed that their child needs attention all the time and that they would not leave their child to his/her own devices. It was apparent, that most of the mothers approached their child with a little more empathy

and would almost try to avoid a stressful situation for their child than allow their child to deal with a stressful situation. Most of the mothers did not want to expose their child to people's comments or stares whereas the fathers felt that children should learn how to deal or cope with it. In my opinion both parents were trying to protect their child in some way. The constant watching over the child or having to get up and do something, took its toll on some parents' relationships. This was *Mrs Hammond's* experience with her husband (now deceased):

"At times it did (place strain on their relationship), because I found out that he was like jealous, like he would tell me I'm spending more time with the child than with him. And I had to explain to him, this is a special needs child, it's not just any baby, you have to watch her all the time".

Mr and Mrs Davids also experienced differences at times. *Mrs Davids* reported that if her child called during the night, she would get up every time irrespective of how many times the child would call. She expressed how she would want *Mr Davids* to act immediately when *Yaasien* makes requests but *Mr Davids* refused many times. *Mrs Davids* responded:

"I don't think we agree on everything ... I stand up whenever he (Yaasien) calls. Not him (pointing to husband)."

Although these parents did not agree on everything, it was clear that they supported each other though. *Mr Andile* seemingly, dismissed his wife's emotional reaction when it came to the child socialising. This is what he said:

"it was only the mother, not me. I was okay. I told her (the mother) to leave her. She must be with others".

Mr Andile had a personal and cultural challenge. He had to make a mental adjustment upon the arrival of his new baby (*Suzy*) as his cultural upbringing caused him not to have understanding and acceptance of a child with a disability. He mentioned that within his culture, people do not accept this (Down Syndrome) and that it was not easy for him. It was clear that *Mr Andile* loved his daughter and would change anything to accommodate her. I commend him for making the

adjustment despite his cultural heritage and being a dominant figure within his culture.

Throughout the interviews, it was very evident that these parents approached their children in a loving manner. All parents had solid foundations in their religion or faith and it appeared that this was part of their coping mechanism. It was my observation that *Mrs Hammond* had strong faith as she said:

“without that (GOD), I would’ve given up long time ago, because it’s a hard road”.

Mr and Mrs Davids are devoted religious parents. This is what they had to say

“God doesn’t give us something that we can’t handle and that is how we believe”.

Mr Andile believed that his daughter’s operations being postponed every time, was God’s way of dealing with the situation

“I thought it was God saying she must not have the operation.”

4.3.3. Main theme 3: *Resilience*

4.3.3.1. Sub-theme: *Faith/religion/culture/acceptance*

The participants came from very different religious and cultural backgrounds. The common factors were the socio-economic status, the special school and their children with Down Syndrome. It became very apparent as the different interviews were conducted, that each parent accepted their child based on their religious beliefs. Although *Mrs James* did not mention much about her faith or God, said the following:

“They mustn’t look at the child’s disability, raise him as normal because God made us normal never mind the disability”.

Mrs Hammond felt that *Mishca* is the reason she has a closer relationship with God and that *Mishca*’s birth has been pre-ordained by God:

“I wasn’t so close to God the way I am now. But when Mishca was born, it drew me closer ... God gives you a child for a reason ... Just be there for the child”.

Mr and Mrs Davids accepted their child because they also believed:

“This is what God has given us and we must accept it. It is our child ... if you are a religious person, you must believe this is what God gave you.”

Despite *Mr Andile’s* cultural challenges, he made significant changes for the sake of his child. This, together with his faith and tremendous love for his child, allowed him to accept his child. Many of the parents found comfort and strength in their faith. Their initial anxiety, fear and worry was eased through their faith which brought about acceptance of their child and their situation. This was *Mrs Hammond’s* response about her everyday situation:

“must I go through this alone. Then I speak to God”.

4.4. Conclusion

With the theoretical framework for this study, it is clear that the parents’ ability to provide or meet the developmental care needs of their individual children, were hampered by their environment. Within the microsystem, the children’s development was altered by the genetics of the parents. The child’s development was influenced by the knowledge and lack of knowledge by the parents. In the case where children had guardians, the lack of knowledge also impacted on the development of the child. The school and family which also forms part of this system either influenced the individual families in a positive or negative way. Most of the participants indicated that they had some support from families and the school though. Within the exosystem of the model, is the community, social services and health care. From the findings, it is clear that most parents did not get the medical, financial or psychological support from these entities. This had a huge impact on the parents as they were not able to meet the developmental needs of their children.

Within the macrosystem, it is the long standing legacies of apartheid that has impacted on the economic and financial establishment of the parents. Although, South Africa has a new

constitution to accommodate all its people, the political and economic effects will always remain. This unfortunately, impacts on the lives of parents and their children. According to these parents, living in the low socio-economic areas affected how they have to raise their child with DS. Many of them indicated that they do not allow their children to play outside in the community as the communities are gang-ridden and crime is rife. Many if not all of the South African contextual risk factors explained in chapter 2, are the harsh reality of the parents in this study. One parent mentioned the struggle with mental health issues due to contextual factors. These findings can be linked to previous research of parents within these types of communities. The effects of living within poverty was clear.

It was clear from the findings above that these parents managed to raise their child with Down Syndrome despite the context, the demands and lack of resources in their communities. Many of the parents had traumatic and emotional experiences regarding their child's diagnosis and the comorbid health issues. They have experienced many similar and different challenges in meeting the physical, emotional, social, educational as well as the day-to-day demands of their child. These parents did everything they could do meet these demands of their child. When considering the overall emotional experiences of the parents, it was clear that many of the parents went through many personal hardships. Not one parent mentioned that they have received any counselling to assist them through this emotional and challenging journey.

Despite the challenges, it was quite apparent throughout the interviews that parents have also experienced personal growth, joy and overall enrichment in life. Some of the mothers were quite emotional during the interviews and yet, they smiled and spoke with so much affection for their child.

One of the main factors that stood out was the resilience of these parents in the face of so much adversity. Their socio-economic living conditions were not of the best but they persevered. Parents felt empowered as they could openly share advice for other parents, teachers and other professionals about what they think could help parents who have children with Down Syndrome and live in similar contexts.

In this chapter, the researcher presented the context of the study, the research findings and discussion, in relation to the current study. Some of the data were presented in tables to illustrate the similarities, categories, themes and sub-themes that emerged during the process

of data analysis. Verbatim quotes were used to substantiate the experiences of the different participants. The findings were discussed within the theoretical framework of the study.

Chapter five comprises the recommendations based on the findings, as well as a discussion on the strengths and limitations of the study.

CHAPTER FIVE

SUMMARY OF FINDINGS, STRENGTHS, LIMITATIONS, RECOMMENDATIONS, CONCLUDING REMARKS

5.1. Introduction

This chapter is the culmination of the qualitative research process and presents a summary of the findings, the strengths and limitations of this current study. Recommendations based on the findings are presented, as well as the concluding remarks.

5.2. Summary of the findings

These findings can be linked to the literature, as discussed in Chapter 4 and 2. A study by Carr, Linehan, O'Reilly, Walsh and McEvoy (2016: p. 69) revealed that parents' initial emotional response to their child's diagnosis of an intellectual disability, was that of shock, anxiety and anger. This correlates to a local study by Barr, Govender and Rencken (2016: p. 929), who focussed on caregivers' perspective on raising a child with Down syndrome in Kwa-Zulu Natal. Based on the findings of the current study, it was evident that most of the parents experienced shock and anxiety. Their (unspoken) expectation of having a "normal" child, was not fulfilled. For the mothers it was this fear and anxiety that raised concerns as to how people would treat their child and how they would manage to raise their child considering their circumstances.

The emotional journeys of the parents were quite thick with colourful descriptions of the highs and lows they had experienced. It was apparent that parents needed support, but did not receive the necessary support throughout their respective journeys. Many of them had some family and professional support much later after the initial diagnosis. It was evident that most families lacked support networks. This could have been due to the fact their family members did not live close to them, and that life within their communities did not offer that support. Despite the initial lack of information and communication from the medical professions, most parents had early medical intervention for their child. The toy library at Red Cross Hospital seemed to have been the most significant support structure for these parents, during the early years of their child's life. The Down Syndrome Support Group was a major support structure for one of the parents. All the parents reported not having resources and support services or access to these,

in their community. Due to the financial constraints of many parents, they were not able to access private professionals for assistance. These parents have endured many challenges and their resilience is commendable. The data revealed that these parents can relate to each other in many ways.

Parents reported that having a child with Down syndrome improved their overall family relationships. It was my observation that due to the difficult and complex experiences parents had as a direct result of raising a child with Down syndrome within this socio- economic context, they somehow felt more equipped for life than parents who did not have children with Down syndrome.

5.3. Strengths of the study

The qualitative design of the study has allowed the researcher to access first-hand knowledge and experiences from the participants. It gave insight into the parents' world. The data collected represents the complex emotional journeys of parents' experiences. This information has enhanced our understanding and brought about a new appreciation of their experiences of raising a child with Down syndrome within their context.

The interviews conducted, created a platform where parents could share their personal perspectives and experiences. It was my observation that parents were excited and grateful to share their stories and lived experiences despite the negative emotions. It was quite apparent, that these parents have not had the opportunity to talk about their experiences. There were many incidents that were undoubtedly, visited for the first time in many years. Parents could laugh about certain events in their lives and yet they could also speak with much pain in their voices, of the personal hardships they have endured. The data collected through these interviews, highlighted the achievements of the parents as well as the need for support in many areas of their lives.

Parents involved in this study, acknowledged that people's situations are different and that each child with Down syndrome, is unique. However, they felt that experiences of their unique journeys with their children have brought about confidence and, it has enriched and empowered their lives. Based on this, they felt they could share some advice with other parents in similar situations, with teachers and professionals as to how to assist parents who have children with

Down syndrome.

Advice to parents who have children with Down syndrome and other disabilities included:

- Accept your child
- Love your child
- Have faith
- Join a support group
- “take it one step at a time, accept what is coming, deal with it when the problem comes to you” (P5)

Advice from parents to teachers who work with children diagnosed with Down syndrome and their parents included:

- Communicate with the parents at all times regarding behaviour, homework, etc.
- Share their knowledge of Down syndrome with parents.
- They should follow the positive behaviour modelled by the parent of the child.
- Interact more with the parents.

Professionals referred to are the doctors, psychologists, therapists, etc. The participants in this study have the following points of advice to professionals involved with parents who have children with Down syndrome:

- Be more accessible, assist or refer parents to other professionals.
- Explain in detail so parents can understand.
- Acknowledge the experiences and knowledge of parents.
- Arrange for home visits to support the families.
- Assist with referrals for grants soon after the child is born.

This study has also highlighted the need for resources and support services within the community. Throughout the interviews, was the marked reality of parents not having and not being able to access support services or resources in the community. Although many of the

communities have community health centres, these centres are restricted to an intake of a certain number of people per day. Many of the community health centres are not accessible at night and people have to go to a designated day hospital for the area which they live in.

The information gathered is extremely valuable and significant to other parents or care-givers and other individuals who work with parents in similar socio-economic contexts. This study presented information that creates an opportunity for the NGO's, education, mental health, medical and social development sectors, to develop effective and efficient systems in low socio-economic areas, that could support parents who have children with Down Syndrome.

5.4. The limitations of the study

One of the limitations was the sample size. Ten invitations were given to the school-based occupational therapist who sent these out to the parents who have children diagnosed with Down syndrome. Only the parents of six children indicated they would participate. This would have been ten parents altogether but only five parents arrived for the interviews. Although, these parents contributed valuable information, the sample size was quite small yet sufficient for the study. A bigger sample size across different schools and different low socio-economic areas, would increase the credibility, dependability and validity of the study. The findings can, therefore, not be generalised.

The limitations included a novice researcher. My skills and possible lack of skills, could have influenced the way I collected, analysed and interpreted the data. I trust that my best was sufficient to generate a quality study.

Another limitation was conducting the interviews in English using an interview guide. Although this particular information was part of the informed consent form and it was explained to each participant before the interviews were conducted, all participants agreed to do the interviews in English. It is my opinion that all the parents were not able to express themselves in a comfortable manner. Some of the participants spoke a bit of Afrikaans in between. Of these Afrikaans quotes that were used for the data analysis, were translated. Due to the language barrier which became quite evident during the first interview, the questions were narrowed down for the remaining interviews. However, this possible language barrier was navigated successfully.

5.5. Possible recommendations

It is important to acknowledge the significant role of the medical staff towards the parent at the birth of a child with Down syndrome or any other disability. Based on the findings, it was evident that parents did not receive adequate information or the relevant communication, regarding their child's diagnosis and the possible comorbid health conditions at birth or soon after. This highlighted the need for medical professionals to consider the plight of the parents when their child is born with Down syndrome or any other disability for that matter. This by implication, displays a lack of respect towards the parent as a patient in a critical situation. Collaboration between professionals and parents can enhance the knowledge of the parents and equip them to have a positive approach to raising their child in the face of adversity.

Collaboration between a school and parents cannot be emphasised enough. A good relationship enhances parent involvement, parent participation in school activities and involvement in their child's continuous growth and development. This type of relationship is significant of a reciprocal benefit to both parties including the child.

The findings also drew attention to the plight of our parents in communities that lack resources and support services. This dire need calls for collaboration between the different sectors across our society such as NGO's, community-based organisations, private professional individuals, including our corporate businesses. This would also include parents in the community supporting one another.

5.6. Concluding remarks

The main purpose of this study was to gain in-depth knowledge and understanding of how parents in a specific context such as a low socio-economic area, manage to meet the developmental care needs of their child with Down syndrome. The qualitative research process addressed this by conducting interviews, analysing that data and produced themes that were common across the different units of analysis. The parents involved in this study have given a glimpse of their day-to-day struggles and the realities of their world. They have allowed for insight into their colourful yet complex world. These findings project their lived experiences within the different systems as described by Bronfenbrenner's bio-ecological model. As a novice researcher, I would hope that the findings of this study could create opportunities for

further research in this field and that action would be taken to implement support structures for parents within these contexts.

5.7. Conclusion and Reflective notes

This final chapter presented the summary of the findings, the strengths and limitations of the study as well as possible recommendations and concluding remarks. Through this qualitative research process, I was afforded the opportunity as a novice researcher, to gain significant insight into the world of the parents living in these socio- economic conditions and trying to raise their child with Down syndrome to the best of their ability. I have complete reverence for these parents as they have to endure hardship on almost a daily basis and that is their norm. Despite their challenges, it was evident that these individual parents undoubtedly love their child. I sincerely hope that as professionals we will be able to effectively respond to the needs of our parents in our poor communities.

I would like to honour the parents in this study by quoting the following as this quote represents them:

(Professor Kader Asmal, Minister of Education: 2001)

“Although the particulars of their lives might differ, millions of mothers and fathers around the world, in both industrialised and developing countries, share the same story: finding and making time, investing energies, stretching resources to provide for their sons and daughters. Their days are consumed in helping their children grow strong and healthy, protecting, teaching, guiding, encouraging their talents and channelling their curiosity, delighting in their enthusiasm and their accomplishments. They search for advice and counsel from informal support networks and community agencies as they struggle, often against great odds, to do right by their children”

(Republic of South Africa [RSA]. Department of Education [DoE]. (2001). Education White Paper 5: p. 3).

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ADDENDUM A: REC LETTER OF APPROVAL



UNIVERSITEIT
STELLERBOSCH
UNIVERSITY

NOTICE OF APPROVAL

REC Humanities New Application Form

29 September 2018

Project number: 0678

Project Title: Parents' perspectives on the developmental care needs of a child with Down Syndrome

Dear Mrs Debbie Meyer

Your response to stipulations submitted on 5 September 2018 was reviewed and approved by the REC: Humanities.

Please note the following for your approved submission:

Ethics approval period:

Protocol approval date (Humanities)	Protocol expiration date (Humanities)
16 July 2018	15 July 2019

GENERAL COMMENTS:

Please take note of the General Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

If the researcher deviates in any way from the proposal approved by the REC: Humanities, the researcher must notify the REC of these changes.

Please use your SU project number (0678) on any documents or correspondence with the REC concerning your project.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

FOR CONTINUATION OF PROJECTS AFTER REC APPROVAL PERIOD

Please note that a progress report should be submitted to the Research Ethics Committee: Humanities before the approval period has expired if a continuation of ethics approval is required. The Committee will then consider the continuation of the project for a further year (if necessary)

Included Documents:

Document Type	File Name	Date	Version
Proof of permission	SCHOOL PERMISSION LETTER	27/03/2018	
Proof of permission	WCED APPROVAL LETTER 2018	27/03/2018	
Data collection tool	INTERVIEW GUIDE FOR PARENTS FEB 2018	27/05/2018	
Research Protocol/Proposal	RESEARCH PROPOSAL END JUNE 2018	27/06/2018	
Informed Consent Form	REVISED PARENT CONSENT FORM MARCH 2018 (11)	27/06/2018	
Default	invitation to participate in a study	27/06/2018	
Default	RESPONSE LETTER REC-HUMANITIES END JUNE 2018 (1)	27/06/2018	
Default	RESPONSE TO REC STIPULATIONS 5 September 2018	05/09/2018	
Default	Review Board Letter	05/09/2018	

If you have any questions or need further help, please contact the REC office at cgraham@sun.ac.za.

Sincerely,

Clarissa Graham

REC Coordinator: Research Ethics Committee: Human Research (Humanities)

National Health Research Ethics Committee (NHREC) registration number: REC-050411-032.
The Research Ethics Committee: Humanities complies with the SA National Health Act No.61 2003 as it pertains to health research. In addition, this committee abides by the ethical norms and principles for research established by the Declaration of Helsinki (2013) and the Department of Health Guidelines for Ethical Research: Principles Structures and Processes (2nd Ed.) 2015. Annually a number of projects may be selected randomly for an external audit.

Investigator Responsibilities

Protection of Human Research Participants

Some of the general responsibilities investigators have when conducting research involving human participants are listed below:

1. Conducting the Research. You are responsible for making sure that the research is conducted according to the REC approved research protocol. You are also responsible for the actions of all your co-investigators and research staff involved with this research. You must also ensure that the research is conducted within the standards of your field of research.

2. Participant Enrollment. You may not recruit or enroll participants prior to the REC approved date or after the expiration date of REC approval. All recruitment materials for any form of media must be approved by the REC prior to their use.

3. Informed Consent. You are responsible for obtaining and documenting effective informed consent using only the REC-approved consent documents/process, and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Please give all participants copies of the signed informed consent documents. Keep the originals in your secured research files for at least five (5) years.

4. Continuing Review. The REC must review and approve all REC-approved research proposals at intervals appropriate to the degree of risk but not less than once per year. There is no grace period. Prior to the date on which the REC approval of the research expires, it is your responsibility to submit the progress report in a timely fashion to ensure a lapse in REC approval does not occur. If REC approval of your research lapses, you must stop new participant enrollment, and contact the REC office immediately.

5. Amendments and Changes. If you wish to amend or change any aspect of your research (such as research design, interventions or procedures, participant population, informed consent document, instruments, surveys or recruiting material), you must submit the amendment to the REC for review using the current Amendment Form. You may not initiate any amendments or changes to your research without first obtaining written REC review and approval. The only exception is when it is necessary to eliminate apparent immediate hazards to participants and the REC should be immediately informed of this necessity.

6. Adverse or Unanticipated Events. Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research-related injuries, occurring at this institution or at other performance sites must be reported to Mielene Fouche within five (5) days of discovery of the incident. You must also report any instances of serious or continuing problems, or non-compliance with the REC's requirements for protecting human research participants. The only exception to this policy is that the death of a research participant must be reported in accordance with the Stellenbosch University Research Ethics Committee Standard Operating Procedures. All reportable events should be submitted to the REC using the Serious Adverse Event Report Form.

7. Research Record Keeping. You must keep the following research related records, at a minimum, in a secure location for a minimum of five years: the REC approved research proposal and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence from the REC.

8. Provision of Counselling or emergency support. When a dedicated counsellor or psychologist provides support to a participant without prior REC review and approval, to the extent permitted by law, such activities will not be recognized as research nor the data used in support of research. Such cases should be indicated in the progress report or final report.

9. Final reports. When you have completed (no further participant enrollment, interactions or interventions) or stopped work on your research, you must submit a Final Report to the REC.

10. On-Site Evaluations, Inspections, or Audits. If you are notified that your research will be reviewed or audited by the sponsor or any other external agency or any internal group, you must inform the REC immediately of the impending audit/evaluation.

ADDENDUM B: WCED LETTER OF APPROVAL

Audrey.wyngaard@westerncape.gov.za

tel: +27 021 467 9272

Fax: 0865902282

Private Bag x9114, Cape Town, 8000

wced.wcape.gov.za

REFERENCE: 20170406 –9852

ENQUIRIES: Dr A T Wyngaard

Mrs Debbie Meyer
77 Richmond Street
Goodwood
7460

Dear Mrs Debbie Meyer

RESEARCH PROPOSAL: PARENTS' PERSPECTIVES ON THE DEVELOPMENTAL CARE NEEDS OF A CHILD WITH DOWN SYNDROME

Your application to conduct the above-mentioned research in schools in the Western Cape has been approved subject to the following conditions:

1. Principals, educators and learners are under no obligation to assist you in your investigation.
2. Principals, educators, learners and schools should not be identifiable in any way from the results of the investigation.
3. You make all the arrangements concerning your investigation.
4. Educators' programmes are not to be interrupted.
5. The Study is to be conducted from **24 February 2018 till 29 September 2018**
6. No research can be conducted during the fourth term as schools are preparing and finalizing syllabi for examinations (October to December).
7. Should you wish to extend the period of your survey, please contact Dr A.T Wyngaard at the contact numbers above quoting the reference number?
8. A photocopy of this letter is submitted to the principal where the intended research is to be conducted.
9. Your research will be limited to the list of schools as forwarded to the Western Cape Education Department.
10. A brief summary of the content, findings and recommendations is provided to the Director: Research Services.
11. The Department receives a copy of the completed report/dissertation/thesis addressed to:

**The Director: Research Services
Western Cape Education Department
Private Bag X9114
CAPE TOWN
8000**

We wish you success in your research.

Kind regards.

Signed: Dr Audrey T Wyngaard

Directorate: Research

DATE: 20 February 2018

**ADDENDUM C:
SCHOOL LETTER OF APPROVAL**

ADDENDUM D: INVITATION



UNIVERSITEIT•STELLENBOSCH•UNIVERSITY
jou kennisvenoot • your knowledge partner

Dear Parent/s

You are invited to participate in a research study conducted by DEBBIE MEYER, a registered student in Masters in Educational Psychology at Stellenbosch University. Ultimately, the results of this research will contribute to the thesis of the researcher. The criteria for this study is to be a parent of a child with Down Syndrome living in a non- affluent area. Should you be interested to participate in this study your valuable contribution will provide information that will help other parents in similar contexts, teachers, psychologists, other professionals, researchers, and the broader public out there to gain more insight into parents' perspectives on the developmental care needs of their child with Down Syndrome. This study will be conducted in English.

Should you be interested to contribute to this study please return this letter to Mrs Velda Van Schalkwyk (school-based Occupational Therapist).

Please tick the appropriate block:

I am interested

I am not interested

Name & Surname of child: _____

Name & surname of Parents: _____

Contact details: _____

I, Mrs Debbie Meyer, will be in contact with you if you have indicated that you are interested to participate in this study. If you are selected, then further details will be explained.

Thank you for your response.

Kind regards

Debbie Meyer

July 2018

Single man ✓

UNIVERSITEIT-SELLENBOSCH-UNIVERSITY
jou kennisvennoot • your knowledge partner

Dear Parent/s

You are invited to participate in a research study conducted by DEBBIE MEYER, a registered student in Masters in Educational Psychology at Stellenbosch University. Ultimately, the results of this research will contribute to the thesis of the researcher. The criteria for this study is to be a parent of a child with Down Syndrome living in a non- affluent area. Should you be interested to participate in this study your valuable contribution will provide information that will help other parents in similar contexts, teachers, psychologists, other professionals, researchers, and the broader public out there to gain more insight into parents' perspectives on the developmental care needs of their child with Down Syndrome. This study will be conducted in English.

Should you be interested to contribute to this study please return this letter to Mrs Velda Van Schalkwyk (school-based Occupational Therapist).

Please tick the appropriate block:

I am interested I am not interested

Name & Surname of child: _____

Name & surname of Parents: _____

Contact detail: _____

I, Mrs Debbie Meyer, will be in contact with you if you have indicated that you are interested to participate in this study. If you are selected, then further details will be explained.

Thank you for your response.

Kind regards

Debbie Meyer

17 July 2018

ADDENDUM E: CONSENT FORM



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvenoot • your knowledge partner

STELLENBOSCH UNIVERSITY PARENT CONSENT TO PARTICIPATE IN RESEARCH

Parents' perspectives on the developmental care needs of a child with Down Syndrome

You, as parents, are asked to participate in a research study conducted by DEBBIE MEYER, a registered student in Masters in Educational Psychology at Stellenbosch University. Ultimately, the results of this research will contribute to the thesis of the researcher. You were selected as participants in this study because your valuable contribution will provide information that will help professionals, researchers, and the broader public out there to gain more insight into parents' perspectives on the developmental care needs of their child with Down Syndrome in a low socio-economic area.

1. PURPOSE OF THE STUDY

The purpose of my study is to look at parents' perspectives on the developmental care needs of their child with Down Syndrome in a low socio-economic area.

2. PROCEDURES

As a participant, you may be asked to take part in an interview which may last up to a 1 hour 30 min. A follow up interview may be requested if needed. The interview will be completely voluntary and will take place at the school at a time which is convenient for you. All interviews will be recorded. People who will have access to the data collected will be myself (the researcher) and my supervisor. The researcher will transcribe the interviews recorded. If you would like to see the written version of the interview, then I would be happy to share this with you.

3. POTENTIAL RISKS AND DISCOMFORTS

Chances are that you might experience some emotional discomfort while answering questions about your relationship with the child. However, if there is anything that makes you uncomfortable or that might inadvertently upset you, you may stop the interview. Should you need a counsellor due to emotional discomfort, please feel free to contact Ms Lungako Mweli (Counselling Psychologist) on 083 925 2759. This will be a service free to you as a study participant only. Please contact me (the researcher) should you need transport to the psychologist. All costs in this regard will be covered by the researcher.

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

Your answer will provide information that will help other parents in similar contexts, teachers, professionals, researchers, and the broader public to gain more insight into the parents' perspective on the developmental care needs of their child with Down Syndrome.

5. PAYMENT FOR PARTICIPATION

Your decision to participate in this study will be absolutely voluntary. No payment will be made for participating in the study. However, I will reimburse transport costs incurred by you for the sake of an interview.

6. CONFIDENTIALITY

All efforts will be made to keep any information confidential that is obtained in connection with this study and that can be identified with you and will be disclosed only with your permission or as required by law. Your name will not be mentioned in the report thesis. Pseudonyms will be used in a case where a name has to be mentioned. All interviews will be conducted in English and take place at the school which would be a central meeting place for the parents. The researcher will arrange with the school principal for a room where interviews can be conducted without any disturbances. This will ensure your privacy while doing the interviews as well ensuring confidentiality of the information shared during the interviews. All data collected will be handled and stored safely to ensure your absolute confidentiality. The researcher (DEBBIE MEYER) will transcribe the interviews as it will enhance the ethical conduct of privacy and confidentiality.

7. PARTICIPATION AND WITHDRAWAL

You may choose to participate or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any question(s) and still remain in the study, or I may withdraw your participation if circumstances arise which warrant doing so. Any data received from participants who decide to withdraw, will be

destroyed unless permission to use the data already collected is expressly given by the participant/s withdrawing from the study. Data collected and used will be stored for a period of 5 years after which it will be destroyed.

8. IDENTIFICATION OF INVESTIGATORS

If you have any question or concerns about the research, please feel free to contact one of the following persons:

- Dr Lorna Dreyer, my supervisor: lornadreyer@sun.ac.za
- Or myself, Debbie Meyer: 0824497764 or debbiemeyer525@gmail.com

9. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development at Stellenbosch University.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to _____ (participant) by DEBBIE MEYER in ENGLISH and I am in command of this language or it was satisfactorily translated to me. I was given the opportunity to ask questions and these questions were answered to my satisfaction. I hereby consent that I will participate in this study. I hereby agree to be contacted for a follow up interview if needed. I have been given a copy of this form.

Name of parent

Signature of parent

Date

Name of parent

Signature of parent

Date

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ [He/she] was encouraged and given ample time to ask me any questions. This conversation was conducted in English.

Signature of Investigator

Date

ADDENDUM F: INTERVIEW GUIDE

DEBBIE MEYER (M. ED PSYCHOLOGY)

STUDENT NO: 17697794

The interview guide has been constructed in such a way that it covers many different themes such as diagnosis, disability, different developmental stages, parenting styles, education, perspectives of developmental care, etc. These themes will allow the researcher to achieve the research goals.

1. Tell me about your family and the position of your child with DS.
2. Can you tell me about (your child's) diagnosis? (who told you, when, where, etc)
3. Was the diagnosis explained to you as parents?
4. Was the possible changes and impact it would have on your lives explained?
5. How did (child) diagnosis impact on your life as:
 - 5.1 individuals
 - 5.2 parents
 - 5.3 the family in the first few years?
6. How did (child) diagnosis impact on (child) life? Do you think it had an impact on the child?
7. what were the challenges you faced in the beginning stages of the diagnosis?
8. what would you say were the physical, social, emotional and demands/challenges when (child) **was a baby & how did you meet the child's demands**
9. what would you say were the physical, social, emotional and demands/challenges when (child up **Toddler? & how did you meet the child's demands**
10. what would you say were the physical, social, emotional and demands/challenges when (child) was **young (6-9) & how did you meet the child's demands**
11. what would you say were the physical, social, emotional and demands/challenges when (child) became a **teen? & how did you meet the child's demands**
12. How did you manage the educational demands? Where did you go and who did you see to assist you in this regard?
13. What would you say were the challenges regarding the educational demands?
14. Were the teachers at the past and/ or current school very helpful? In which way?
15. In which way did they assist you or influence your perspective with the development/developmental care needs of your child?
16. How did you manage to provide for and support your child as a baby with very specific developmental needs?
17. What services were available to you once you came home from hospital with the baby?

18. Could you access these services easily?
19. If yes, how did you access the services? If not, what were the reasons?
20. Do you feel you had support from your family and the community?
21. Do you feel that your life was different having a child with Down Syndrome compared to other mothers or parents with typical developing children?
22. Do you feel that living in your area affected the way you could support your child? If so, in which way?
23. Are there any people in your community that have influenced you on how to meet the developmental care needs of your child?
24. What according to you as parents, would be the most important factor in raising a child with Down Syndrome in your area (context)?
25. What would you consider as good strategies to raise a child with Down Syndrome in your community?
26. What are the resources available to you in your community that would help you meet developmental demands of your child?
27. Do you have a support network within the community? If so, what is your support network within the community or outside of your community?
28. Do you feel raising your child with Down Syndrome in this community has caused you to be at a disadvantage in any way? Why?
29. Do you think your parenting style has allowed you to look at your child's developmental needs differently or influenced your approach towards your child?
30. Do both parents approach the child in the same manner or do you think your parenting styles are very different? If so, do you think both ways are effective?
31. What advice would you give to
 - parents in a similar situation?
 - teachers regarding their role towards families who have children with Down Syndrome?
32. Do you wish to add any other relevant information?

ADDENDUM G: EXAMPLE OF TRANSCRIPT

- Diagnosis
- Fear/Denial
- blame
- birth rechanges
- Medical Card.

- told family
- God/Religion Muslim

- Comparison to other condit.
- Support

Rec: 001

23/08
25/08
26/08
Thema 3
26/08

Debbie	Hi This is an interview with Mr and Mrs: ... on 31 July. Welcome thank you very much. like I said I do appreciate it. So just tell me about your family and the position of ...'s birth, is he the only child, second child, first child
Mrs	He is the baby, the third child
Debbie	Third child. Okay, uhm so just tell be about Omar's diagnosis. Who told you when and where was this
Mr	Okay, so the first time she went for a scan with the pregnancy of ... Uhm the doctor at Groote Schuur, she measured the fetus now right?
Debbie	Yes
Mr	So she told us that uhm there is a one percent change that he will be down syndrome
Debbie	Wcw
Mrs	She actually said that 99.9%she is going to say that it is not, but she cant say he's not down syndrome and then he is
Debbie	Okay
Mrs	But then she said he is 99.9% not
Debbie	Okay
Mrs	But then he was born with...
Mr	But we actually forgot about him because you know the chances are high... <i>that it won't be</i>
Debbie	Of course ... yes
Mr Fisher	We talked about it and uhm... When he was born ... uhm you know.. I picked it up immediately but I kept it to myself. • Fear/Denial?
Debbie	Okay
Mr	And uhm... you mos know <i>women</i> women fault there hormones... they very emotional and so
Debbie	Where you uhm.. Did you give natural birth if I may ask?
Mr	Yes, natural birth
Debbie	So you were there and you saw the baby first?
Mr	I wasn't there with the birth. I was kind of sleeping in the car (Chuckle)
Debbie	Chuckle
Mrs	(Chuckle) But it happened so quick
Mr	But I was about fifteen minutes too late.
Debbie	Okay. Okay
Mr	I went out to go have a smoke
Debbie	Ya. Ya.
Mr	... in the car and I fell asleep in the car. Chuckle
Debbie	(Chuckle) Okay. Okay. Was it natural birth if I may ask? <i>for take me? repeat</i>
Mr	Yes. Yes (chuckle)
Debbie	So did you get to see baby immediately?
Mrs	No..
Debbie	No..
Mrs	But he wasn't crying <i>I think he wasn't crying</i>
Debbie	Okay And then tell me... when did they tell you about the diagnosis?
Mrs	I think it was about two weeks after that...?
Mr	Ya... That was up and down from Hanover Park Clinic to Somerset Hospital and they communicated by letter via the doctors and nurses...

play back him out

①

ADDENDUM H: EDITORIAL CERTIFICATE

20 February 2019

To whom it may concern

Dear Sir/Madam

RE: Editorial Certificate

This letter serves to prove that the thesis listed below was speed-read for slight changes to grammar, punctuation, and spelling, because of time constraints. The editing, as well as the overall layout and style was executed by myself, publisher/proprietor of Aquarian Publications, a native English speaking editor.

Thesis title

PARENTS' PERSPECTIVES ON THE DEVELOPMENTAL CARE
NEEDS OF THEIR CHILD WITH DOWN SYNDROME:

Author

Debbie Lucillê Meyer (nee Loots)

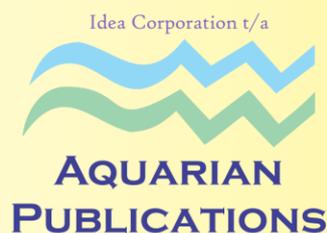
The research content, or the author's intentions, were not altered in any way during the editing process, and the author has the authority to accept or reject my suggestions and changes.

Should you have any questions or concerns about this edited document, I can be contacted at the listed telephone and fax numbers or e-mail addresses.

Yours truly



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