

**Towards indigenous social work practice guidelines for assisting  
African families raising children with Down syndrome**

by

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## **DECLARATION**

Student Number: 32711905

I declare that "Towards indigenous social work practice guidelines for assisting African families raising children with Down syndrome" is my own work and has not been submitted in any form for another degree at any university or other institution of tertiary education. Information derived from the published or unpublished work of others has been duly acknowledged in the text and a list of references is given.

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**SIGNATURE**

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**DATE**

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## LIST OF ACRONYMS

AMA	Advanced Maternal Aged
ASASWEI	Association for South African Social Work Education Institutions
CHE	Council Higher Education
CSWE	Council on Social Work Education
DSA	Down Syndrome South Africa
DSD	Department of Social Development
DW&PD	Department of Welfare and Population Development
DoH	Department of Health
DS	Down Syndrome
GP	Gauteng Province
HIV/AIDS	Human-Immuno Deficiency Virus/Acquired Immune Deficiency Syndrome
IFSW	International Federation of Social Work
LP	Limpopo Province
TOP	Termination of Pregnancy
WHO	World Health Organisation
NASW	National Association of Social Workers
NHLS	National Health Laboratory Services
NWP	North-West Province
MP	Mpumalanga Province
SACSSP	South African Council for Social Service Professions
USA	United States of America

## **ABSTRACT**

It is common knowledge that the social work profession in Africa, including its theories, methods, and models, has been implanted from the global North (Europe) and North America. Scholarship within social work has confirmed that there are challenges of relevance and appropriateness of Westernised social work interventions, and consequently, their effectiveness in a context outside the Euro-North American axis. It is against this backdrop that the researcher explored the African family, its experiences, and its coping strategies when raising a child with Down syndrome as well as the nature of social work services they received and whether such services were congruent with the family's existential condition and subjectivities. A retrospective qualitative study following a phenomenological design was conducted. Research data were collected from a sample drawn using purposive and snowball techniques, through the use of semi-structured interviews. Qualitative data analysis process adapted from Terre Blanche, Durrheim and Painter (2006:33) was used. The findings revealed the existence of a paradoxical relationship between Eurocentrism underlying social work practice and the Afrocentric worldview. The typical African family raising a child with DS was found to be characterised by a unique form and structure consistent with a clan system different from the conventional Eurocentric concept of family. It was also found that despite the pressure and assault exerted by modernity, colonization and apartheid on the traditional African clan system, it remained resilient and retained its unique character distinct from the western nuclear family system. In relation to dealing with challenges associated with raising a child with DS, the African clan's concerns were found to transcend pre-occupation with the etiology and treatment of the condition as emphasized in the western paradigm. Without discounting the significance of the etiology and treatment of the condition, the African clan draws on its spirituality and affection to consider the purpose and function of the condition in the bigger scheme of things. Social work as a helping profession seemed to be unpopular amongst African clans raising children with DS. The findings were used to develop indigenised social work practice guidelines for social workers assisting African families raising children with DS.

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## **CHAPTER ONE**

### **INTRODUCTION**

#### **1.1 Background to the research study**

The birth of a child with intellectual disabilities such as Down Syndrome (subsequently referred to as DS in this thesis) in any family is a traumatic experience with adverse psychosocial effects in the long run. The DS condition was first described in 1866 by Langdon Down (Mueller & Young, 2005:53), and up to this stage review of the literature has revealed that few papers have dealt with the psychosocial impact of having a child with DS on the family. DS is also known as trisomy 21 in cytogenetics, a study of human chromosomes (Mueller & Young, 2005:53). It is known to be the most common chromosome abnormality found in children.

There are several other known chromosomal abnormalities in addition to DS. Together they account for about 50% of all spontaneous miscarriages and 0.5-1% of live born babies (Lampret & Christianson, 2007:215; Mueller & Young, 2005:54). It was earlier referred to as Mongolism, as children with DS look like people from Mongolia with their up-slanting palpebral features or features of the eyes (Leshin, 2000). It is characterised by mental retardation, heart defects, distinct facial features and an increased susceptibility to leukaemia as well as the early onset of Alzheimer's disease (Lampret & Christianson, 2007:515; Harper, 2004:30). It affects 1 in 525 individuals world-wide (Kromberg, Sizer & Christianson, 2013:415).

The DS condition is also common in South Africa, affecting about 1.8-2.01 per 1000 live births in both urban and rural African populations (Kromberg et al., 2013:415; Lampret & Christianson, 2007:515). The maternal risk for giving birth to a child with DS increases with maternal age and the risk is higher at an advanced maternal age (AMA), that is any age above 35 years (Mueller & Young, 2005:55). In industrialized countries such as Europe and America, the minority of infants with DS are born to mothers of AMA, whereas in South Africa more than 50% of children with DS are born to women of AMA (Lampret & Christianson, 2007:516). Individuals with DS are able to survive to their 4th-6th decade of life with good medical and social care, while others die in the

first year of life, usually due to heart problems (Leshin, 2000). Heterogeneity is one of the remarkable aspects, wherein individuals with DS exhibit a wide variety of clinical features. For example, the range of mental retardation among children with DS is very broad and the degree of developmental delay varies significantly (Leshin, 2000).

In South Africa, the birth prevalence of DS is higher due to a high percentage of childbearing women being of AMA as shown by Lampret and Christianson (2007:516). Furthermore, the situation is exacerbated by the lack of access to antenatal screening and prenatal diagnosis services to most people and, worse still, the option of termination of pregnancy being either not available to a large proportion of the population or not accessed by those who have it available (Schön, 2004:42). As a result, giving birth to a child with DS becomes a very difficult and traumatic experience. Accordingly, the situation dictates that the necessary support services including social work not only be available, but have to reach the family at its level of understanding and belief system to maximise benefits and effectiveness. Thus, it is the researcher's view that proper care and management of the condition of a child with DS at both medical and social level requires an organised and coordinated approach.

As postulated by Christianson and Modell (2004:236), the degree of quality of medical and social life of infants born with a severe congenital disorder depends on the level of development and availability of health and social services. The above position is further consolidated by Christianson, Howson and Modell (2006:31) when they argue that contrary to high-resource settings such as Europe and America, where up to 70% of all birth defects can be avoided, infants' lives saved or disability considerably improved, the situation in low-income settings such as Africa is different as the majority of affected infants die undiagnosed or are disabled. More than 30% of infants with a serious congenital disorder in middle-income countries, and at least 50% in low-resource countries die within infancy or childhood (Christianson et al., 2006:32).

The population prevalence of DS in high resourced countries is close to 70% of its birth prevalence and the life expectancy of individuals with DS has improved in recent years compared to what it was decades ago as complications are treated and educational as well as social support is available (Christianson et al., 2006:32). However, contrary to the situation described above concerning high resourced areas, in lower resourced

nations, the mortality in infancy and early childhood of children with DS is far greater (Christianson et al., 2006:32). Earlier on, Christianson, Zwane, Manga, Rosen, Venter, Downs and Kromberg (2002:180) documented that two out of three children with DS in South Africa die prior to 2 years of age. Lampret and Christianson (2007:516) documented that 65% of children with DS die before 2 years of age. For those children who survive, there is lifelong chronic disability with needs that exceed those of most other children. These needs include early developmental enrichment programs, such as physiotherapy and speech therapy (Cohen, Nadel & Madnick, 2002:12).

Based on the available literature reviewed on the burden of congenital disorders worldwide, the researcher argues that the impact of these disorders has been greatly underestimated in low-income nations such as South Africa on the ground that there are no concerted efforts by government, civil society and the private sector to combat the scourge of congenital abnormalities, including DS. The researcher observed that limited resources for screening and diagnosis are available at selected urban centres and nothing is provided for in rural areas, yet care and management of these conditions place a huge burden on the national fiscus. Limited resources have been channelled to research and development in this sector resulting in a lack of up to date information and statistics on the incidences and prevalence of DS in South Africa. Christianson and Modell (2004:220) confirm these observations when they argue that it has not been recognised, especially in middle and low-income nations, that there is a great need, and that possibilities exist for care and prevention of congenital disorders.

Nevertheless, it is worth-noting that, prognosis improves as care improves and that an increasing proportion of infants with congenital disabilities survive as services become available. Furthermore, as the number of infants that survive increases, the number requiring care increases incrementally (Christianson & Modell, 2004:220). Care for individuals with congenital disorders includes diagnosis, therapeutic intervention and genetic counselling with psychosocial support (Christianson et al., 2006:31; Christianson & Modell, 2004:223; WHO, 2000:28).

According to Christianson and Modell (2004:220), medical care for children with DS requires an organised approach of assessment, monitoring and vigilance. These authors further state that once an early and correct diagnosis of DS is made in the

individual, associated problems can be recognised. The treatment regime for an individual who has been diagnosed with DS includes cardiac evaluation with treatment, if necessary; prompt treatment of infection, regular dental care, monitoring of thyroid function and treatment of hypothyroidism when indicated and prevention of obesity (Roizen & Patterson, 2003:1282). The best option for neurodevelopmental therapy to help an affected individual in middle and low-income settings is community-based rehabilitation run by primary health care practitioners with local people trained to assist (Christianson & Modell, 2004:223).

It is significant to note that Christianson and Modell (2004:220) further stress that there are numerous simple therapeutic interventions for people with DS that can be given in the primary health care setting. They also observed that the more complex interventions such as cardiac assessment and surgery for children with DS may be available at some secondary and tertiary hospitals. However, they caution that, often, the more complex procedures such as cardiac surgery may not be offered to a child with DS, because of lack of facilities and competing priorities (Christianson & Modell, 2004:224). According to the South African government's Policy Guidelines for the Management and Prevention of Genetic Disorders, Birth Defects and Disabilities, DS is listed as one of the four congenital conditions on the Health Ministry's priority list (Department of Health, 2005:12). The policy indicates that prevention of DS can be done at various levels such as primary, secondary and tertiary levels.

However, the situation on the ground suggests otherwise. It appears that there is lack of implementation of this policy, given that only few tertiary hospitals employ medical geneticists and have fully functional teams rendering genetic services. The situation at primary health institutions such as clinics as well as district hospitals is worse, according to the researcher's observation. They all do not have genetic services and as such prevention of DS as a genetic condition is virtually impossible without dedicated personnel and resources allocated at these levels for the prevention of DS.

Given the immense psychosocial effects of giving birth to a child with DS, both the mother and family require comprehensive psychosocial support to deal with the unexpected loss of an anticipated healthy child. The researcher observed that, in compliance with the need for a holistic approach to social service delivery, few

hospitals in South Africa have put in place all necessary support services to achieve a holistic approach in total patient care, and this includes the integration of health care social workers who are charged with the responsibility of helping patients and their families deal with the psychosocial implications of their medical conditions. This presents opportunities and challenges for social workers. The opportunity presented is for social workers to practice within a multi-disciplinary medical setting and the challenge presented is for social workers in health care to take on the mantle of acquiring appropriate knowledge and skills in various medical specialties that they work in, such as genetics in primary health care. Having acquired such knowledge and skills, social workers in health care will be able to develop relevant intervention protocols or models that can help curb the unbearable psychosocial and financial costs of raising a child with DS.

The researcher argues that the identification of an abnormality in a child is a shocking and traumatic experience for parents. Parents react with dismay on hearing that their new-born child has an abnormality (Cowles, 2000:13). DS is one of the few conditions associated with mental retardation where the diagnosis can be made during the pre-natal stage or shortly after birth (Cowles, 2000:13). It is the researcher's observation that the birth of a child with DS does not only create financial, social and medical burdens for the individual or family, but it also places fiscal strain on the state, as the child will need social assistance in the form of a disability grant as practiced in South Africa, special school, regular medical attention, and in some cases, major surgical procedures, as well as institutionalisation in case of serious disability.

The Department of Health (2005:53) in its policy document on the Management and Prevention of Genetic Disorders, Birth Defects and Disabilities estimated that, on average, the cost of caring for a child with DS can amount to about R15 000 - R20 000 per annum for basic medical care. Where necessary, an additional cost of R50 000 can be incurred for a heart surgical procedure. These figures must have doubled over the years through inflationary pressures, but current estimates are not available.

Given the above background, it is clear that the family of children with DS will need long-term professional psychological and social support. The researcher observed that the DS condition has not always been known or understood amongst African families

until recently when pre and post-natal diagnostic technology was introduced to few academic hospitals in South Africa. The African family raising a child with DS had to rely on its traditional belief system to interpret and manage the condition without any professional psychosocial support. The researcher acknowledges that a lot has changed since, including improved access to early diagnostic technology in some geographic areas, as well as counselling and support services. There is no literature available on social work services rendered to African individuals and families of children with DS in South Africa. Consequently, there are no specific protocols or guidelines developed for social work services with individuals and families raising children with DS. The researcher observed over the years in health care practice that most African families raising a child with DS, who are fortunate enough to get a confirmed diagnosis of the condition, get referred for psychosocial support at the health care institution. The initial counselling is done by a genetic counsellor (most of which are not social workers), who in turn refer the client to a health care social worker and a support group for on-going support. The health care social worker will in-turn refer the client to welfare services or the Department of Social Development (DSD) for processing of social security aid in the form of a disability grant and other relevant welfare services.

In an effort to obtain literature on indigenisation of social work services to African families raising a child with DS, the researcher observed that nothing has been written yet. As a result, the theoretical discussion on indigenisation centres on social work broadly instead of it being specific to indigenisation of social work services to African families raising children with DS; hence the exploratory nature of this study as it seeks to explore a phenomenon less understood or less-studied.

Generally, the extent, to which the intervention of a social worker will be effective in any given situation, will depend heavily on the degree of congruence between the worker's approach and the client's frame of reference as defined by their socio-cultural backgrounds (Osei-Hwedie, 1997:41). The lack of fit between the social worker's approach and the client's frame of reference or worldview may undermine the effectiveness of the helping process and breed role confusion on the part of the client and the social worker (Thabede, 2008:234; Kuse, 1997:19). This applies to social work services rendered to African families raising a child with DS. Because of the strong

traditional belief that characterises African families and the fact that the DS condition has always been understood and given a cultural interpretation, any form of social support should move from or start where the client is. Failure to do so will result in the client failing to understand, own and control the helping process. Inevitably, this would result in the process being fruitless and unsustainable.

As Thabede (2008:234) argues, one of the contributory factors to the confusion of the professional role of social work in African communities is “the adoption of the value base of social work in its pure form from the American societal value system”. For instance, Thabede (2008:234) highlights the fact that social work’s belief in the worth and dignity of the individual, the right of the individual to determine his/her own destiny, and the recognition of the individual’s potential regardless of colour, creed or national origin to govern himself and others in a democratic society militates against the African worldview’s emphasis on collective good. Pointedly, Thabede (2008:235) postulates that individual concerns are subordinate to group interest in the African cultural context. Whatever Africans do is based on group efforts, hence the support of extended family throughout Africa. A more detailed discussion on the African family and the nature of its evolution over time is presented in Chapter 4 of this thesis.

The clan name system is also another form of group support and group cohesiveness. Whenever there is festivity, a ceremony, or a crisis in most African families, relatives and households belonging to the same clan pool their resources together both in cash and in kind (Tshabalala, 1991:73). Further to demonstrate this collective tendency, Tshabalala (1991:74) notes this group emphasis by indicating some of the basic values of Africans as: importance of the family; the importance of the group; respect for elders; fear of God; as well as a deep commitment to sustaining meaningful community life through shared produce, problems and sorrows (*Ubuntu*). From the above illustrations of the concept of *ubuntu*, it appears that group consciousness and group cohesiveness are central characteristics of the African society. Most of the African ethno-cultural practices are based on values and philosophies that conflict with conventional values and philosophies underpinning counselling as a process (Kuse, 1997:21). Such values are inherent in the traditional patriarchal family system, the philosophy of keeping family matters within the family and not to open up for strangers, and the traditional beliefs in ancestral powers and witchcraft (Thabede, 2008:239; Tshabalala, 1991:74).

The African belief in sympathy militates against empathy in counselling. Congenital abnormalities and mental retardation as found in children with DS are perceived largely as either a curse or the result of witchcraft in most of the black ethnic cultures. This understanding is not supported by social work interventions underpinned by the western cultural orientation, and this leads to a discrepancy between the actual felt needs and the helping process offered. Thabede (2008:235) argues that it is inappropriate to apply Eurocentric theories of human behaviour to explain the behaviour of Africans as the two are underpinned by extremely different worldviews.

“Social workers and other human service professionals have long been questioning the appropriateness and effectiveness of first world theory and practice within an African context” (Kuse, 1997:19). Within social work as a profession, scholars and researchers have highlighted the biggest challenge facing social work practice in the 21st century as being that of the need for the proper indigenisation of practice models. This need has necessitated a search for social work practice that can promote the type of development that both practitioners and client systems can understand and relate to. This search has led to the emergence and analysis of concepts such as indigenisation (Osei-Hwedie, 2002:312).

Indigenisation refers to a process towards achieving appropriateness of theories and practice, as well as values, norms and philosophies that form the basis for practice (Osei-Hwedie, 2002:312). Specific to such indigenous appropriateness, Midgley (2008:31) defines indigenous social work as “appropriateness, which means professional social work roles must be appropriate to the needs of different countries and social work practice”. In addition to this, practice must also follow societal procedures, norms, ideas and practices. Indigenisation, thus, also translates into practice within a socio-cultural context (Osei-Hwedie, 2002:312). It is the researcher’s view that in Africa, social work’s dependence on Western ideas and worldview makes it ineffective in the face of prevailing social problems and the demands of practice imposed by contextual issues. The researcher has reviewed several pioneering studies and indigenised practice models that have been experimented with around the world, including mainland China, Australia, Botswana (Africa), Canada, Jordan, and Singapore. The studies reviewed affirm the importance of further debates about the negative and positive implications of indigenisation in any self-respecting society.

The indigenization movement in the social sciences began to gain momentum in the early 1970s (Boroujerdi, 2002:41; Atal, 1981:189) and reached its heyday in the late 1970s. Walton and Abo El Nasr (1988:149) identified the fact that the notion of indigenization appeared in relation to social work for the first time in 1971, when the fifth United Nations (UN) international survey of social work training used it to refer to the inappropriateness of American social work theories for other societies. In reference to this, Boroujerdi, cited in Grant and Short (2002:41), proposed that new concepts and theories based on indigenous intellectual traditions, history, and culture should be developed to build indigenous social sciences.

Scholars such as Osei-Hwedie and Rankopo (2008:137); Gray (2004:625); Midgley (2008:31), have argued that social work has a significant role to play in the improvement of the quality of life of developing societies. To be effective, however, it has to shed its foreign character and redefine its central focus. Thus, according to Osei-Hwedie and Rankopo (2008:138), social work practitioners and educators must understand their own environment in order to formulate the basis of the profession. Gray (2002: 22) notes the fact that the problem confronting African social work has to do with its past, a past in which indigenous ways of helping did not feature but in which foreign developments, thoughts and theories were preferred.

It is for this reason that this study was pursued. It emanated from and builds on an earlier study that the researcher conducted between the years 2003 and 2006, where the psychosocial needs and coping strategies of African mothers following the birth of a child with DS were explored. The study was qualitative and smaller in scope focusing on mothers only, immediately after giving birth to a child with DS. The unit of analysis was the phenomenological experience of African mothers. In this study, the researcher focused on the African family raising a child with DS and the nature of social work services that they received. The researcher used the resultant in-depth understanding of the above to develop indigenised social work practice guidelines for individuals and families raising a child with DS as presented in chapter six of this thesis.

## **1.2 The problem statement**

The researcher observed that there is a general lack of literature on social work services to individuals and families raising children with DS, despite it being a debilitating condition with immense negative psychosocial effects. The lack of literature in this area is in itself a problematic gap that must be closed. The DS condition is common worldwide but, in South Africa, studies of black neonates with DS have shown that 50% of infants with DS were born to mothers of advanced maternal age, which is the age above 35 years (Christianson et al., 2006:10). Therefore, this means that more children with DS are born to elderly African couples who are likely to be more inclined to traditional cultural beliefs and practices.

It is noteworthy that while the birth of a child with DS in a family is a traumatic experience with adverse psychosocial effects, for the historically disadvantaged black African families as compared to their previously advantaged white counterparts, the experience of raising a child with DS or any abnormalities is even more difficult, given the harsh historical, social and economic predicaments that characterise black African communities (Department of Social Development, Department of Women, Children and People with Disabilities and the United Nations Children's Fund, 2012:43). Furthermore, there is a stigma attached to giving birth to a child with congenital malformation or mental retardation as found in DS among African families (DSD, DWCPD & UNCF, 2012:45; Rosenkranz, 2004; Christianson et al., 2002:180). In African families such a birth is widely viewed as a curse by the ancestors for some form of misdeed either by the parents or by the family as a whole (Christianson et al., 2002:180). Anecdotal incidents have been reported about gross neglect and abuse of children with DS or any other condition accompanied by intellectual disabilities (Rosenkranz, 2004). These include incidents of children being chained and locked up in houses for years by parents or families who did not want community members to see any child with a disability (Rosenkranz, 2004). There are also serious challenges resulting from a lack of resources and the inherent socio-economic inequalities that continue to prevail in black African communities (Pillay, 2001:23). The majority of black Africans, particularly those residing in deep rural areas, are still trapped in extreme poverty with little or no access to basic resources and infrastructure (Pillay, 2001:23). The above challenges further complicate and frustrate parental efforts to providing care and support for the child with DS (DSD, DWCPD & UNCF, 2012:43). In addition to the overwhelming psychological reactions associated with discovering that the child has

DS, raising such a child within a black African family is extremely difficult given the reality of widespread poverty and economic deprivation (DSD, DWCPD & UNCF, 2012:45). Thus, the socio-cultural and economic landscape of African families raising children with DS presents challenges and opportunities that call for empirical research to identify, harness, use and build up a well-honed responsive service-delivery system.

Given the above background, African children with DS, as well as their families, are generally considered to be at risk of resorting to dysfunctional coping mechanisms owing to the heightened stress levels and their worldview. The risk emanates from the resultant overwhelming sequence of psychosocial reactions, which are capable of disintegrating the family unit as a system. Either the parents of the child with DS, or the child him/herself, may adopt dysfunctional coping mechanisms.

There is a general lack of local literature that specifically examines the role of African traditional and cultural heritage as well as African spirituality as a frame of reference in the social work helping process. Where such literature exists, if ever, it is mainly flimsy, dated and limited in scope. As a result, the researcher relied heavily on such dated literature to highlight issues pertaining to the lack of fit between professional social work practice and indigenous African cultural and spiritual belief systems and practices. The African families raising children with DS have to navigate and juggle between the two worlds of the African worldview and the world of professional help deeply embedded within the Euro-North American worldview. Therefore, the main problem addressed in this study emanates from the lack of prominence of the African cultural heritage and spirituality in social work practice with African families raising children with DS. Thus, the purpose of this study was to use an understanding of the nature of the African family raising children with DS, its experiences and coping mechanisms, and the opinions of social workers providing services to the family in order to develop indigenous social work practice guidelines for assisting such families in raising children with DS.

### **1.3 The rationale for the study**

As argued by Fouché and De Vos (2011:51), topics for social work research should come from the day-to-day activities and interactions encountered in the work situation. This, for the researcher, has been the main source of motivation. The researcher is positioned at a vantage point of being an African who worked with African communities as a social worker, and has experienced the disconnections and incongruences between the nature of mainstream social work and the worldview of Africans. He is a member of both worlds, and he has navigated and negotiated the intersections between the African worldview and the world of professional social work practice. Such experience has prompted the researcher to want to develop an in-depth understanding of the nature of the African family, its experiences and its coping mechanisms when raising a child with DS as well as how all of these relate to the social work services they receive. The study, therefore, sought to supplement, and not even remotely replace, what was known about mainstream social work practice. This enabled the development of a hybrid system integrating both western and African philosophies within which the western concepts can find their proper African domestication. The practice guidelines generated from this study will serve to set parameters and add signposts for practice in the way African families raising children with DS can be treated and particular events handled.

### **1.4 Philosophical grounding and theoretical perspectives**

This thesis was developed from an African existential philosophical lens using three theoretical perspectives: social constructionism and constructivism, the eco-systems theory, and the strengths perspective. The choice of this philosophical stance and the theoretical frameworks was motivated by the fact that the study was essentially foregrounded on both ontological (concerning the nature of reality and being), hence a philosophical stance and epistemological (concerning the study of the nature of knowledge and knowledge acquisition) assumptions; hence the theoretical perspectives. The study sought to unearth the nature of reality and being of African families raising children with DS as well as the nature and acquisition of knowledge and how the African families come to know their realities and identities. The African existential philosophy was engaged from relativist ontology to inform the chosen

epistemological stance. The relativist ontology rests on the acceptance of multiple versions of reality as being equally valid (Burr, 2003:15). Meaning that one's attachment to the African existential philosophy does not necessarily render other varied existential realities and stories less significant or invalid, but rather view them as contributing to the shared co-construction of the meaning-making process.

The African existential philosophy provided a congruent philosophical grounding for the study given that the unit of analysis was the lived experiences of African families raising children with DS. The choice of this philosophical grounding was based on the assumption that the unique African families' existential condition and subjectivity cannot be adequately analysed and understood from a western perspective that currently dominates social work knowledge, but rather from within a standpoint of the Afrocentric critical analysis (Sithole, 2016a:26). The use of an African existential philosophy effectively represents a shift in the geography of reason that is necessary for the authorization of the subjectivity of the African lived-experience in order to combat subjugation and western hegemony (Sithole, 2016b:178). The social constructionist and constructivist theory was deployed within the Afrocentric horizon to illuminate how knowledge is socially constructed at both collective and personal levels respectively within the African existential condition. The eco-systems perspective was also deployed from an Afrocentric viewpoint to highlight the interconnectedness and oneness of elements and sub-systems making up the cosmic system of the African world inhabited by African families raising children with DS. Finally, the strengths perspective was deployed from an Afrocentric vantage point to underscore the resilience linked to the inherent strengths and resources embodied within the African families' existential condition and subjectivity.

#### 1.4.1 The Africana existential Philosophy, and Afrocentric cultural essence and thought

The Africana existential philosophy, as More (2008:47) calls it, was derived from the seminal Fanonian invention of the concept of the black subject. According to More (2008:47), "Africana existential philosophy is the emergence of black selfhood, black suffering, identity and liberation". He urges that this philosophy is enunciated from the lived experience of being black in an anti-black world as well as how blacks should militate against such an existential condition to chart a way for liberation. Consequently, Sithole (2016a:24) characterised Frantz Fanon as the figure of the black subject following his eloquent and tenacious conceptualisation of how black subjects

struggle with the kind of subjection that questions their humanity. According to Sithole (2016a:25), Fanon propounded the notion of the existential condition of the black subject in an anti-black world and advanced that such existential condition should be engaged from the '*ontological zero point*' which means that they should be understood from their lived experiences and their form of living that is reduced to non-existence (lack of ontological density), but possessing the ability to emerge. This is also known as '*existential phenomenology*', according to Sithole (2016b:182).

Thus, through 'existential phenomenology' (the life world as experienced), the actual experience of being black in the anti-black world is effectively and subjectively accounted for and articulated. Using Fanonian meditations, Sithole (2016b:179) unmasks and exposes the scandal of subjection of Black subjects "who are caught in the world which locates and incarcerates them in the positionality of the other". He further argues that this positionality places black subjects in the exterior to the zone of life and they are effectively condemned to a 'zone of non-being'. Similar sentiments were earlier on expressed by Biko (1978/2004:102). Fanon (1952/2008:82) diagnosed and exposed the scandal of colonial deception which he advances that it has and still is subjecting black subjects to the long dogmatic sleep of subjection, hence the call by Biko (1978/2004:102) for the re-awakening of the sleeping masses. This is against the backdrop and understanding that subjection's main object is to produce black subjects who are ontologically void and thus necessitating a philosophical intervention that does not only help us make sense of the condition, but also instructive and actionable as an instrument facilitating the liberation of and emergence of black subjectivities with full ontological density that was previously blocked. The African families' experience is hereby recuperated from the zone of non-being as they deal with the complications of DS.

Despite Fanon's continued relevance to the contemporary black world, some critical scholars acknowledged his contribution with reservations. They advanced that Fanon's thinking was based on real, lived experiences, but his assertions may not find practical expression in today's world and consequently reduced to metamorphic thought (Mbembe, 2012:20). However, Sithole (2016b:181) maintains that given the unequal and antagonistic world that black subjects find themselves caught up in the clutches of the anti-black world, is a clear demonstration that Fanon's thought has not mutated to

being metamorphic, but still carries weight in the face of the spectre that continues to haunt the present existential condition of the black subjects.

According to Fanon (1952/2008:166), the anti-black world is underpinned by a dehumanising project of subjection that criminalises black subjects for articulating and asserting their own ontological density. He argues that this anti-black world does so by masking its sadistic elements through liberty, equality and justice, which from the structural positionality of blackness, mean their very antithesis. As categorically captured by Gordon 2010, cited in Sithole (2016b:181) “the anti-black world is the world of subjection which poses as reason, whereas it is unreason”. A close analysis of Fanon’s (1952/2008:166) sense of being black in the anti-Black world reveals a series of descriptions which include amongst others; “a positionality of absolute dereliction; existential crisis; state of permanent subjection; a feeling of inferiority which is made to be a feeling of non-existence; imposition of pathological existence; a body reduced to tabula rasa; a razzmatazz in need of the order of disciplinary invasion”.

Thus, the African existential philosophy as an ontological stance represents a unique philosophical position for understanding the African experience, even as it relates to coping with DS. Additionally, several other African scholars followed after Fanon and expanded the African philosophy. It is not the purpose of this thesis to dwell on an exhaustive list of African scholars and their contributions, suffice it to mention few that are most relevant to this study. They include Steven Bantu Biko’s *‘Black Consciousness movement’*, Molefi Kete Asante’s *‘Afrocentric theory and philosophy’* as well as Dr Ani Marimba’s *‘Yurugu and African Asili’*.

Building on Fanon’s earlier work, Biko (1978/2004:26) highlights the value of the black nation to assert itself by stressing that “... each group must...attain its style of existence without encroaching on or being thwarted by another ... Africa must inevitably exhibit African values and be truly African in style”. In agreement with Fanon’s concept of ‘existential phenomenology’, Biko (1978/2004:29) lamented that real African subjectivity should emerge “not from a detached point of view and an oversimplified premise ..., but from and by blacks themselves, a living part of Africa and of her thought”. He also articulated his views on subjection and the kind of havoc rigged by the machinery of colonialism that produced “a kind of black man who is only man in form without own standards and outlook, killed by spiritual poverty”.

Molife Kete Asante is the founder and principal theorist of Afrocentricity (Turner, 2002:712). As argued by Asante (2006:647), Afrocentricity as a theoretical perspective and philosophy sought to convey the profound need for African people to be re-located historically, economically, socially, politically and philosophically from holding up the margins of the American and European's world. This, according to Asante (2006:647) would ensure that Africans free their minds and shift from being decentered to being centered on African cultural heritage. This would indeed, enable Africans to develop and promote their heritage and contribute to the world of knowledge. Afrocentricists contend that humans cannot divest themselves of culture (Asante, 2006:648). He further asserts that Afrocentricity as a movement becomes the key to the proper education of children and the essence of an African cultural revival and indeed survival.

According to Asante (2006:649), there are several key characteristics that set apart and distinguish Afrocentrism as a unique paradigm from Eurocentrism. Firstly, contrary to the Eurocentric racial views that elevated European experience and downgraded others, Afrocentrism had no racial or ethnic consciousness and no hierarchy. It did not claim to occupy all spaces and times. Secondly, Afrocentrism as a pluralist philosophy was characterized by respect for all cultural centers (Asante, 2006:649). Thirdly, while data takes precedence over context in the Eurocentric world, cultural context and location takes precedence over data in the Afrocentric world. Fourthly, culture is the main driver in the orientation to centeredness. Lastly, the individualism, nuclear family and competition found in the Eurocentric paradigm is countered by collectivism, communalism, cooperation and an extended family system in the African context demonstrated through *Ubuntu* (group consciousness and cohesion). While the researcher does not wish to delve into the detail relating to evolutionary changes pertaining to the above aspect, it is worth noting that culture is not static. It changes over time in response to changes in the socio-economic and political environment. The African cultural landscape, too, has been disrupted by various forces including colonial oppression and deliberate attempts by colonial forces to destroy African culture (epistemicides and genocides) as well as concomitant attempts to modernize and replace African cultural reality with the perceived superior western cultures.

Lastly, Dr Marimba Ani, an African anthropologist who is part of the movement for African-centred education coined the phrase 'Yurugu', which theorises the European cultural thought and behaviour juxtaposing it against the African cultural 'Asili' (the

seed) which stands for the essence of the African cultural thought and behaviour (Ani, 1994:24). Her anthropological intervention provides an epistemological stance based on the African existential philosophy. She argues that the African cultural 'Asili' is based on a cosmic view of reality where everything is connected, interrelated and interdependent. She advances that Africans strive to be in tune with the universe instead of imposing their own order on it. As such, African cultural thought and behaviour derive their knowledge of reality from a diversity of sources including objectivity, spirituality and intuition. Her theoretical intervention contrasts the African approach with the European one to reality and ways of knowing in such a manner as to show that contrary to the cyclical/spiral African approach that seeks balance, spiritual growth, life giving and receiving, creation through the symbolic, rhythm, power through connectedness and spiritual whole, the European approach seeks to subdue/destroy, and also seeks power and to control. The following table describes the contrast between the two approaches:

**Table 1: Contrasting the African from the European approach to reality and ways of knowing (Ani, 1994:43)**

<b>African</b>	<b>European</b>
Sacred	Profane/Cursing/Blasphemy
Holistic	Segmented
Unifying	Dichotomous, Splitting
Integrative	Separating
Connected to nature	Alienated from nature
Complementarity, Appositional	Confrontational, Oppositional
Harmony	Conflict, Tension
Symbol	Object
Reciprocity	Exploitation
Inspirational	Manipulative
Cyclical, Spiral	Linear
Spiritual concepts	Intellectual denial of spirit
Spirit and matter joined	Separation of spirit and matter
Communalistic	Individualistic
Cooperation	Competition

The researcher employed the African existential philosophy together with its associated theoretical constructs to conceptualise the findings of the study aided by the three

theoretical perspectives of social constructionism and constructivism, eco-systemic and strengths perspectives respectively.

#### 1.4.2 Social Constructionism and Constructivism

This study was approached from a social constructionist and constructivist epistemological stance. According to Andrews (2012:41), the social constructionists view knowledge as being constructed as opposed to being discovered and, as such, constructionism is unconcerned with ontological issues. Andrews (2012:41), further contends that social constructionists view society as existing both as a subjective and as an objective reality. Consequently, meaning is shared, and it is the same meaning that constitutes reality. Young and Colin (2004:378) advance an argument similar to that of the social constructionist belief in subjective reality that emanates from a matrix of shared meaning. The terms 'constructivism' and 'social constructionism' tend to be used interchangeably and are subsumed under the generic term 'constructivism' particularly by Andrews (2012:41). According to constructionism, the world around us is socially constructed rather than being objective. Constructivism is said to refer to our psychological (cognitive) processes and structures at individual level. In other words, it refers to how we perceive the world as individuals. Constructivism proposes that each individual mentally constructs the world of experience through cognitive processes while social constructionism has a social rather than an individual focus. The social constructionist positionality is chosen for its consistency with the African paradigm that privileges the collective rather than the individual, while the constructivism is also used to explain individual differences or deviation from the collective position.

In relation to the above, Andrews (2012:43) further stresses that the social constructionist theory has similar philosophical roots to the interpretivist approach to thinking, though the two are different. In common with constructionists, interpretivists, in general, focus on the process by which meanings are created, negotiated, sustained and modified (Andrews, 2012:43; Schwandt, 2003:296). According to Andrews, the proponents of these perspectives share the goal of understanding the world of lived experience from the perspective of those who live in it. Both theories arose as a challenge to scientism and have been influenced by the post-modernist movement.

The social constructionist theory views knowledge and truth as created and not discovered by the mind (Schwandt, 2003:233). Following the foregoing logic, the social

constructionist theory was used in this study to make sense of how African families construct their worldview of knowledge and truth about raising a child with DS. As outlined in this theory, the roles of language, culture and belief systems in relation to the construction of knowledge and truth were explored to make sense of the realities of the participants. According to Andrews (2012:42), conversation is the most important means of maintaining, modifying and reconstructing subjective reality. Subjective reality is comprised of concepts that can be shared without problems with others. In other words, there is shared meaning and understanding, so much so that concepts do not need to be redefined each time they are used in everyday conversation and they come to assume a reality which is, by and large, taken for granted.

The social constructionist approach further asserts that researchers are subjectively involved in the work they investigate or explore rather than being objective and detached from the process of enquiry (Andrews, 2012:43). The meaning the researcher attached to the situation under study is considered an important part of the research process as also stressed by the literature (Du Preez & Eskell-Blokland, 2012:45; Burr, 2003:8). This notion allowed the researcher's involvement in the meaning-making process and afforded value to his extensive relationship with the participants and familiarity with the context.

The researcher appreciated the usefulness of the theoretical lenses provided by the social constructionist theory to map out how knowledge is constructed out of the subjective experiences of African families though, ahistorical and apolitical. However, the researcher recognises the fact that the theory is limited given that it is not concerned with ontological questions (concerning the nature of reality and being). As a result, the social constructionist theory is not able to account for the underlying historical and political determinants of the resultant social construction of knowledge. For instance, the social constructionist/constructivist theory does not alert us to the insanity associated with the notion of the fringes and peripheralisation of Africans as illuminated by Afrocentricity in a call to Africans to free their minds and shift from being decentered to being centered on African cultural heritage as asserted by Asante (2006:648).

Using the social constructionist and constructivist theory, the researcher was able to map out social learning and the influence of various socio-political forces shaping the learning process and the ultimate social construction of such knowledge. Amongst key

forces influencing the social learning process are unequal power relations in society driven by structural and institutional discrimination and racism (Asante, 2006:648). It is on the basis of all of the above social anomalies that those amongst the inhabitants of the world whose cultural and spiritual power has been destroyed (epistemicides), and whose life dehumanised, inferiorised and racialised are conditioned (subjection) as inferior (Sithole, 2016b:182). This form of conditioning is artificial, but naturalised form of subjectivity that reinforces and reproduces their subjugation in all aspects of life including knowledge production (Sithole, 2016b:182). Thus the researcher submits that the theory was found to be inadequate in explaining the nature of reality and knowledge, hence the necessity of infusing Afrocentric critical analysis as a philosophical ground upon which a more in-depth critical analysis was undertaken.

Using insights from the study, the researcher interpreted the manner in which African families constructed their realities, and used the insights as a basis for the construction of practice guidelines for helping African families raising children with DS. Consistent with the social constructionist and constructivist theory, and moving from relativist ontology, the researcher believed that the existing unique African concepts are constructed rather than discovered, yet they correspond with something real in the world. In the same breath, the Euro-North conceptualisations are consistent with the existential conditions and realities of their context and may not find expression in the African experience. This is consistent with the idea of subtle realism in that reality is socially defined but this reality refers to the subjective experience of everyday life, how the world is understood, rather than to the objective reality of the natural world (Andrews, 2012:42). As Steedman (2000:58) notes, most of what is known and most of the knowing that is done is concerned with trying to make sense of what it is to be human, as opposed to scientific knowledge. Individuals or groups of individuals define this reality. In the same vein, the researcher in this study was concerned with the nature and construction of knowledge, how it emerged and how it came to have significance for the African society.

### 1.4.3 Eco-Systems theory

Similar to the social constructionist theory, the ecosystems perspective was also deployed from an Afrocentric philosophical grounding. According to Zastrow and Kirst-Ashman (2010:34), the ecosystems theory is used to describe and analyse people and other living systems and their transactions. This perspective is said to fit well with the 'person-in-environment' concept which is the foundation notion in social work and our basis for understanding the dynamics of human behaviour. The eco-systems perspective was selected on the ground that the professional domain of social work is embedded in the said theoretical framework (Ambrosino, Heffernan, Shuttlesworth & Ambrosino, 2012:49). It is also referred to as the Meta theory or an umbrella framework that addresses the relationship, interaction and interdependence between people and their environments (Ambrosino et al., 2012:50). According to Bronfenbrenner, cited in Darling (2007:203), the ecological-systems theory was developed in 1979. She further demarcates the theory into three levels of environments, viz., microsystem level (individual level), mesosystem level (group level), and macro systems (societal level). Elucidating this, Darling (2007:203) further argues that there is a dynamic interplay between the three levels of environments. She asserts the significant role played by the context on the development of the human life-span. The ecological-systems theory, according to Darling (2007:204), sees everything as interrelated and that our knowledge of human development is bounded by context, culture and history. This is consistent with the Afrocentric philosophy's principle of oneness and interconnectedness of all elements in the cosmic system.

However, Becvar and Becvar (2013:18) introduced a different view of the ecosystems theory when they asserted that the theory is underpinned by three main assumptions analyzed in terms of three shifts in viewing human nature and the implications they have for a healthy personality. The analysis begins with the so called Newtonian-Cartesian epistemology, first and second order cybernetics and social constructionism. Cybernetics refers to the science of pattern and organization (Becvar & Becvar, 2013:35).

It is significant that Becvar and Becvar (2013:35) explained the Newtonian epistemology as a mechanistic linear causality approach to human life. This approach to human life according to the researcher's views is effectively and essentially in direct contrast to the African intellectual philosophy and cultural thought that views life as

spiral and cyclical. The Newtonian epistemology is focused on cause and effect and understands reality as objective (Becvar & Becvar, 2013:19), whereas the African philosophy and cultural thought relies on both objective, spiritual and intuitive thought. For instance, on the one hand the objective view of the cause of DS would advance that the condition is caused by failure of chromosomes to split during mitosis resulting in trisomy 21 where three instead of a pair of chromosomes are found on the site of chromosome 21 regardless of where or who the individual is and that advanced maternal age is a risk factor. On the other hand, while acknowledging the objective truth regarding the cause and effects of DS, individuals and families guided by the African worldview would invoke the underlying spiritual and affective inferences. Such inferences may include amongst others, the appreciation that the child with DS is a gift from God and part of a bigger plan for the affected individuals and families.

From isolated, independent units of Newtonian epistemology the shift moves to interconnectedness (orders of feedback), which are the First-order cybernetic view of human life. Second-order cybernetic refers to a shift higher that includes the observer as being part of the context (Becvar & Becvar, 2013:20). In a nutshell, First-order cybernetics on the one hand, looks at the connections between everything in the world without including the observer and the observed. Second-order, on the other hand, makes the connection between the observer and the observed.

Families understood as systems, exchange information with the environment. They are 'self-correcting' cybernetic networks that process information (the input) and govern themselves through rules according to Goldenberg and Goldenberg (2012:23). Rules in this context do not mean morals or principles; they refer to repetitive matters of relationality in families. It could be, for example, that in a family, for generations, children have always greeted adults with both hands or not called parents by their names. These repetitive behaviors are referred to as rules. The families are characterized by openness (continuous flow of information from outside, for example, other families), relationship (mutual interactions of family members), non-summativity (no member of the family is bigger than the rest of the other members) and equifinality (the outcome is always the same due to interrelatedness of the members of the family) (Goldenberg & Goldenberg, 2012:23).

The interrelations are through feedback loops, for example if a child breaks a window, and is punished, the punishment is fed back into the child, causing him/her to be more

careful next time he/she is playing around the window. Families like systems strive to maintain themselves, thus striking a balance/homeostasis (staying the same) (Goldenberg & Goldenberg, 2012:24).

The feedback loops help maintain the balance by creating boundaries or parameters controlled by the rules. The degree, to which these limits allow information to be let into the system/family from outside /other families, will characterize the system as either open or closed. An open family allows more interactions from outside the family as opposed to a closed family (Goldenberg & Goldenberg, 2012:24). These feedback loops do effect changes into the families/systems.

According to Becvar and Becvar (2013:22), there is always an on-going tension between the need of a family to maintain itself (morphostasis) and to change (morphogenesis). This tension calls for circular patterns of interactions where a symptom is involved. A family that is 'healthy' or well-functioning is one that is able to encourage each individual member to realise his/her potential (to develop personal identities), while at the same time allowing them to feel attached to the family group. The realisation of the potential of an individual is an integral part of the African paradigm and is viewed within a collectivistic approach as opposed to the western individualistic approach. A healthy family, therefore, is one that is open and succeeds at balancing the needs of the system with the needs of the individual member, and a healthy personality is one that succeeds in balancing his/her needs with those of the family (Goldenberg & Goldenberg, 2012:24).

An Afrocentric critical analysis of the ecosystems approach exposes and scandalizes the inherent limitation of this approach based on its failure to recognize structural and institutional basis of oppressions and discriminations that exert control on the functioning and regulation of any system including families—overtly and covertly. Such oppressive forces are naturalized and difficult to recognize and address in the absence of a historical and political critical analysis. The Afrocentric critical analysis through its appreciation of historical events that shaped the African existential conditions is able to illuminate such structural and institutional forces that impinged and conditioned the subjective experience of Africans (subjection) and their sacred institutions, including the family. Through this critical Afrocentric analysis, one was able to articulate firmly that the African family system in its current form is not fully self-regulating, but firmly conditioned (subjected) by circumstances of colonial subjugation and subjection

beyond its own control. Therefore, the ecosystems approach as a modern theory, even when applied as a post-modern critical theory remains inadequate in helping us understand the dynamic interaction of systems and sub-systems. However, the researcher recognizes that the approach offers some useful insights that may be taken as first level understanding whose critique offers a much higher level of understanding.

#### 1.4.4. Strengths-based perspective

The strengths-based perspective was also used from an Afrocentric point of view. According to Cummins, Sevel and Pedrick (2006:42), the strengths-based perspective in social work practice springs from the values that permeate the profession, such as inherent worth, human dignity and self-determination. Putting the above values into action requires that we believe in the unleashed power that resides in all human beings and the possibilities of change. Client strengths become the resources for change that move people forward to growth, mastery and self-actualization (Cummins et al., 2006:42; Zastrow, 2004:60). The strengths-based perspective as a theoretical framework provides social work practitioners with an alternative framework for practice that is counter to the deficit model that has dominated human services perspectives (Cummins et al., 2006:43). Notably, Zastrow (2004:60) argues that the strengths perspective is closely related to the concept of empowerment and culturally competent practice.

On the one hand, empowerment is defined as, “the process of helping individuals, families, groups, and communities to increase their personal, interpersonal, socio economic, and political strength and to develop influence toward improving their circumstances” (Zastrow, 2004:60). From an Afrocentric viewpoint, the root cause of social problems is materialism, objectification, individualism and inordinate competition that become a fertile breeding ground for oppression and spiritual alienation (Schiele, 1997:803; Schiele, 2013:17). Thus, the need for empowerment does not arise as people are believed to be inherently capable in the absence of oppression, particularly cultural oppression and spiritual alienation which precludes people from optimal thinking (Schiele, 1997:803; Schiele, 2013:17). Through the use of an Afrocentric lens, the researcher was able to unearth the inherent cultural power and rich spiritual endowments characterising the African family that have been suppressed through the systematic and systemic subjugation of colonisation and apartheid. As a result, African families are not able to fully express their cultural and spiritual power which is the basis

of their unique existential strength. Through this kind of analysis, the researcher was also able to identify the blindingly obvious failures of a litany of empowerment attempts unleashed on Africans flowing from this perspective due to the fact that, however genuine their intentions may be, their embeddedness within an institutionalised, naturalised, oppressive and racist system of colonial and imperialist, neo-liberal Euro-North American epistemology, such attempts were bound to fail. This is due to the fact that they fell short of addressing the structural challenges hindering the inherent abilities of Africans to self-determine on the basis of their cultural and spiritual power.

On the other hand, a culturally competent practice or ethnic-sensitive practice seeks to incorporate an understanding of diverse ethnic, cultural and minority groups into the theories and principles that guide social work practice (Zastrow, 2004:431). It is based on the view that practice must be attuned to the value dispositions related to the ethnic group membership and social class position of clients (Zastrow, 2004:431).

In conclusion, this section dealt with how the three theoretical perspectives used in this study were deployed from the angle of an Afrocentric critical analysis. The thrust of this section is that, the three theoretical perspectives are inadequate for understanding the African families' existential condition in that they form part of the Euro-North American epistemology and do not fully take into account the systematic and systemic colonial oppression that created the African challenges. Therefore, it was necessary to examine the African families' existential condition from their African lenses using the Afrocentric philosophy. As a result, the researcher was able to unearth the real sources of the African family's power in their cultural heritage and spirituality. The theoretical perspectives undergirded by the Afrocentric philosophy were used to foreground the proposed guidelines for social work practice with African families raising children with DS.

### **1.5 The research questions, aims and objectives**

The researcher is of the view that, in undertaking a research project, researchers are driven by a need to answer clearly stated research question(s). Elucidating the foregoing, Grove, Burns and Gray (2013:708) define research questions as "concise, interrogative statements developed to direct studies". Similarly, David and Sutton

(2011:12) explain the research question as the guiding star that helps the researcher to navigate through the research process.

The main research question asked in this study is as follows: “How can one use an understanding of the nature of the African family raising a child with DS, its experiences and coping mechanisms, and the opinions of social workers providing services to the family in order to develop indigenous social work practice guidelines for assisting such families in raising children with DS?” In order to cover the above broad research question comprehensively, the researcher has posed the following research questions:

- What is the nature of the African family raising a child with DS?
- What is the recollection of African family regarding its experiences and coping mechanisms with regard to raising a child with DS?
- What are the perceptions of African families regarding children with DS?
- What are the perceptions of African families in relation to the social work services received whilst raising a child with DS?
- How would African families raising a child with DS like to be assisted by social workers in a culturally appropriate manner?
- What are the opinions of social workers regarding the level of congruence between social work services, the identity, and the experiences and coping mechanisms of African families raising a child with DS?
- What suggestions do social workers have for the improvement of social work services for African families raising a child with DS?

Following the discussion of the research question above, the aims of the study are now outlined. The word ‘aim’ was used for the purpose of discussion in this regard. “The goal is a dream the researcher wants to achieve in research.” (Fouché & De Vos, 2011:104). Furthermore, Fouché and De Vos (2011:105) state that a goal is a “broad and abstract idea towards which research efforts or ambitions are directed”. According to Creswell (2013:134), the aim of the study refers to the statement of the major goal, intent or roadmap.

The broad aim of this study was to develop an in-depth understanding of the identity, experiences, and coping mechanisms of African families raising children with Down syndrome (DS) as well as the opinions of social workers assisting them in an attempt to distil the implications of such and use them to develop practice guidelines for social work practice when assisting the African families with regard to comprehending and dealing with DS. The specific aims of this study are as follows:

- To develop an in-depth understanding of the identity, the experiences and coping mechanisms of African families raising children with DS;
- To develop an in-depth understanding of the perceptions of African families regarding their experience of raising a child with DS as well as the nature of social work services received whilst raising children with DS;
- To explore the views of African families raising a child with DS about how they would like to be assisted by social workers in a culturally appropriate manner;
- To develop an in-depth understanding of the opinions of social workers regarding the level of congruence between their interventions and the nature of the African family, its experiences, and coping mechanisms when raising a child with DS;
- To establish social workers' opinions on how social work services for African families raising a child with DS can be improved and
- To develop practice guidelines directed at social workers providing professional services to African families raising children with DS.

Having outlined the research questions and aims, it is imperative that one also states what the research objectives that were formulated to assist the researcher in answering the research questions were. Grove et al. (2013:708) refer to research objectives as declarative statements that are expressed to direct a study. On the other hand, Fouché and De Vos (2011:94) state that objectives refer to practical steps taken to achieve the aim of the research. All of these statements concur with what is stated by Mouton (2005:240), who argues that research objectives serve as a route to a destination.

Thus, the objectives of this study are as follows:

- To obtain a sample of African families raising children with DS as well as social workers rendering a service to these families, found in and around the provincial boundaries of Gauteng, North-West, Limpopo and Mpumalanga provinces of South Africa;
- To conduct semi-structured individual, family, and focus group interviews with the African families in order to explore their experiences and perceptions in relation to raising children with DS and how they received professional support provided by social workers;
- To conduct semi-structured individual interviews with social workers rendering services to African families raising a child with DS in order to explore their opinions regarding the level of congruence between the services they provide and the nature of the African family, its experiences and coping mechanisms of raising children with DS;
- To sift, sort, and analyse the data, using steps in the methods for qualitative data analysis adapted from Terre Blanche, Durrheim and Painter (2006:33).
- To draw conclusions regarding the implications of the experiences of African families raising children with DS and the opinions of social workers providing a service to them for the indigenisation of social work practice with such families and
- To develop guidelines on how social workers providing social work services to these families could serve them in a manner that would allow them to understand, own and control the help received.

The above objectives enabled the researcher to reach the research goal by answering the research question.

The following section outlines the ethical considerations that were applied in the process of executing this study.

## **1.6 Ethical considerations**

On the one hand, research ethics refers to the rules of good moral conduct (Carey, 2012:25). On the other hand, Fouché and Delport (2011:114) define ethics as a code

of conduct or rules or laws that regulate behaviour. From the above definitions, the researcher deduced that ethics provide parameters and blueprints in the form of moral standards and norms that regulate the conduct and behaviour of researchers. It is imperative, therefore, that researchers act within ethical confines so as to prevent harm and to protect the integrity of participants. The first step by the researcher was to submit an application for ethical clearance to the University of South Africa's Departmental Research and Ethics Committee. Ethical clearance was received from the Departmental Research and Ethics Committee (Addendum I). Various important ethical considerations were taken into account in this study as follows:

- Informed consent

According to Strydom (2011:59), informed consent implies that all possible or adequate information on the goal of the investigation, the possible advantages, disadvantages and dangers to which the participants may be exposed, be discussed with participants. This, from the researcher's point of view, implies that research participants have the right to know the process and consequences of participating in the research before they can decide whether to participate voluntarily or opt out of the study.

The researcher adhered to this ethical principle by conducting information sessions with all potential participants. The sessions were used to give detailed information about the research process, the goals and objectives of the study, the researcher's ethical obligations and the participants' right to volunteer their participation and be able to withdraw their participation at any time and any stage of the research process. In order to ensure that the potential participants understood the process clearly, the researcher gave them time to ask questions and be answered during the information session. The information sessions for the individual social worker and family (clan) interviews were conducted on the same day with the actual interview session due to logistical challenges and consideration for time required to complete all these tasks. However, for the focus groups, information sessions were conducted a day before the actual group discussion session. The researcher facilitated the signing of the informed consent forms only when everyone had understood the process and given the researcher a verbal indication to that effect. The researcher, however, also ensured that participants were encouraged to ask questions throughout the process whenever a need arose.

- Anonymity and confidentiality

The researcher has incorporated anonymity with confidentiality as the two concepts are related and interdependent. Anonymity, according to Hennink, Hutter and Bailey (2011:71) implies that the identity of the participants will be hidden and protected. Hennink et al. (2011:71) argue that anonymity is achieved through putting in place several measures such as removing any identifiable information of the participants from interview transcripts or quotations used. In addition, Greener (2011:146) explains 'confidentiality' as meaning that the research data and its sources remain confidential, unless participants have consented to their disclosure.

Following from the above explanations, the researcher adhered to the principles of anonymity and confidentiality by doing the following:

- Usage of pseudo names for participants and their characteristics;

The researcher created false names to identify participants and their characteristics because the use of real names might have led to associations being made of the research data and particular individuals, consequently resulting in a breach of the principle of anonymity and confidentiality.

- Usage of pseudo names for research sites and their characteristics;

In the same vein as the above, the disclosure of the identifying details of research sites and their characteristics might have led to linkages being made to particular individuals or groups of participants. The researcher, therefore, undertook to avoid such and to rely on pseudo names instead.

- Management of information

According to Strydom (2011:68), the management and storage of research data constitutes an equally crucial ethical consideration. Any access to such data by anyone other than the researcher and those involved in the research constitutes a breach of the principles of anonymity and confidentiality. The researcher, therefore, made sure that all data in the study was stored in a safe place. No any person other than the researcher had access to the hard copies of written materials and audio recordings used in this study except for the research supervisor and the research assistant. The research assistant only had access to the data during the course of data collection (fieldwork). He had no access to the password protected laptop and lockable storage

where the electronic data was stored. The written materials and the digital recorder were stored in a lockable storage at the researcher's private house, and all electronic data stored in the researcher's laptop and access to such data remained password protected.

- Debriefing of participants

According to Strydom (2011:68), debriefing is the responsibility of the researcher to restore the normal state of the participants to where it was prior to the interview. Gravetter and Forzano (2012: 591) stressed that debriefing of research participants should be undertaken at the end of their participation and, in this regard, they concur with Strydom's insistence that the researcher should take responsibility of this process. The above sentiments are echoed by Picardi and Masick (2014: 35) who further argue that the aim of debriefing is twofold: firstly, to ensure that the research participants are not left with negative feelings and, secondly, to receive feedback from the participants regarding their experience of the data collection process.

The researcher accordingly provided the necessary debriefing after the interviews. Additionally, arrangements were made with the social worker from the DSA to be on stand-by for participants on the days of the interviews to provide on-going support if it became necessary. No referral was made as all participants did not show a need for further emotional support after the debriefing session was completed. The nature of this study compelled participants to re-live their emotionally-charged experiences, and this could have evoked emotional reactions of varying significance on participants. The researcher, as a qualified social worker, exercised considerable caution and was observant in order to detect any reactions warranting appropriate steps to be taken. These steps may have included, among other things, referral to a relevant support service where necessary. However, such needs never arose.

### **1.7 Clarification of key concepts**

**African:** "belonging or relating to the continent of Africa or to its countries or people (Ntsoane, 2005:90). The Collins English Dictionary (2014) defines African as denoting or relating to Africa or any of its people, languages and nations or a member or descendant of any of the people of Africa, especially a Black person. For the purpose of this study, "African" referred specifically to black people of African descent, living in South Africa.

**African existential condition/subjectivity:** denotes the way in which knowledge practices are informed by conditioned ways of knowing and consciousness as the way of understanding the self, the lived experience and the world that the self-inhabits. It also denotes the formation of the African subject in the political act of resisting and combating subjection (Sithole, 2016a:25). For More (2008:47), “the African existential condition relates to the lived experiences of Black people in an anti-black world as well as how they militate against such an existential condition to chart a way for liberation. For the purpose of this study, African existential condition or subjectivity refers to the totality of the lived experiences of African people including their history, culture and traditions as shaping the ways of being, knowing and consciousness.

**African family:** Contrary to western society that views the term ‘family’ as generally understood to refer to the conjugal pair who maintains a household with their offspring or adopted children while anyone else outside of this circle is ‘extended family’, the African society generally views "family" as a much wider circle of people related by blood and marriage (Russel, 2003:12). The African family refers to a collectivity of people who live together, whose relationship could be traced through kinship or marriage, and who considered themselves family (Siqwana-Ndulo, 1998:415). For the purposes of this study, the researcher adopted an African conceptualisation of family that is blended and covers cohabiting group of people, usually economically dependent on one another, whose intimate relationships are based on custom and blood. This means that the African family refers to a clan or a collective of people either living together or in separated households, connected by blood and perceived to be one family.

**Afrocentricity/Africanity:** is the way of being, including thinking and writing from the standpoint that privileges Africa as a starting point of subjectivity and analysis thereof (Asante, 2006:648). As a form of African subjectivity, Africanity is combative towards the Euro-North American Empire’s ways of thinking and writing African subjectivity, and it should not be mistaken as either a reactive or corrective discourse, but the affirmation of African subjectivity where African subjects are writing from their own existential conditions (Sithole, 2016a:26). In the same manner, Sherr (2006:5) posits that Afrocentricity refers to self-conscious action that seeks equality for Africans [African American] and improved relations with all people. For the purpose of this study, Afrocentricity is used as denoting the way of being, the way of thinking and

writing from the vantage point that privileges Africa as a starting point of subjectivity and analysis.

**Child:** means a person under the age of 18 (Children's Act 41 of 2007). The same definition was used for the purpose of this study.

**Culture:** According to Brydon (2011:157), culture denotes society's ways of responding to social needs and problems on the one hand. On the other, the words knowledge and culture can be readily interchanged and taken to mean the same (Huggins, Macklin, & Glendinning, 2008:22). For the purposes of this research, "culture" was used in line with the above definitions to refer to both the societal response to social needs and problems as outlined by Brydon (2011:157) and as a knowledge system as defined by Huggins et al. (2008).

**Culturally sensitive social work practice:** is defined as the process by which individuals and systems respond respectfully and effectively to people of all cultures, languages, classes, races, ethnic backgrounds, religions and other diversity factors in a manner that recognises, affirms and values the worth of individuals, families and communities and protects and preserves the dignity of each (Garran & Rozas, 2013:98; NASW, 2008:7). Also known as cultural competent practice or ethnic-sensitive practice it seeks to incorporate an understanding of diverse ethnic, cultural and minority groups into the theories and principles that guide social work practice (Zastrow, 2004:431). For the purpose of this study, Zastrow's definition is used referring to the incorporation of the understanding of diverse ethnic, cultural and minority groups into the theories and principles that guide social work practice.

**Down syndrome:** "A common chromosome abnormality found in children, characterised by mental retardation, heart defects, distinct facial features and an increased susceptibility to leukaemia and early onset Alzheimer's disease" (Mueller & Young, 2001:53; Engelbrecht, Swart and Eloff, 2001:257). For the purpose of the study the above definition was used as is.

**Indigenisation of social work:** Indigenization of social work refers to a process of relating the social work and social work education function to the cultural, political and social realities of a particular country (Brydon, 2011:158). Osei-Hwedie (1993b:20) and Midgley (1983:170) shared similar sentiments explaining indigenisation of social work as referring to the process of making social work theories and practice

appropriate to the values, norms and philosophies of people and their contexts. All elements contained in the above definitions and explanations of indigenisation of social work by Brydon, Osei-Hwedie and Midgley were integrated and used in this study.

**Social work:** The International Association of Schools of Social Work (IASSW) and the International Federation of Social Workers (IFSW) (2014) defined social work as “... a practice-based profession and an academic discipline that promotes social change and development, social cohesion and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and **indigenous knowledges**, social work engages people and structures to address life challenges and enhance wellbeing” (Ng, 2014:127). Social work can also be defined as a profession devoted to helping people to function best in their environment, and which has its own body of knowledge, code of ethics and practice standards (National Association of Social Workers, 2012:23). According to Ambrosino et al. (2008:27) and Cummins et al. (2006:2), social work is defined as an activity that seeks to help individuals, families, organisations, groups, and communities engage resources that will alleviate human problems. In this study “social work” refers to any professional activity by a qualified and properly registered social worker rendering any form of service to African families raising children with DS.

### **1.8 Limitations of the study**

The limitations of this study include amongst others, the following:

- The researcher writes from a vantage point of being an African indigenous scholar, having experienced first-hand the conflict and lack of fit between the professional self and the existential conditions as experienced in personal, cultural and political self. The above makes the research to be an ‘insider’ point of view which can be a limitation given the potential influence of personal biases and subjectivities. As a result, the researcher does not claim any objectivity in this study. It has proven impossible for one to remain objective given that as a social being, one is shaped by specific historical experiences, culture and traditions. Therefore my interaction with the data is influenced by my subjectivity.

- The English language is also a limitation as the lived experiences researched were experienced, thought and narrated in African terms and associated African languages by the participants; but the researcher had to explain them in English. This can be seen as a limitation because not all the concepts had directly correspondent meaning once translated into the English language.
- The study sought to uncover the subjective experiences of African families raising children with DS which in itself is a sensitive matter with immense psychosocial implications, and some participants might have found it difficult to open up and be honest in their responses resulting in skewed findings, a phenomenon known as self-report bias.
- The study relied on cases of families with a child with DS in order to distil implications for the indigenisation of African social work practice. The exclusive focus on a specific social challenge (African families raising children with DS) was for practical and logistical reasons, but it can be limiting when dealing with such a broad topic as the indigenisation of social work practice, especially given the specific and unique factors characterising each social situation. As a result, the findings of this study are specifically for this particular group of participants; hence the guidelines for indigenised social work practice can be found to be not applicable to other groups of clients.
- Due to the fact that the study dealt with a medical condition (DS) and a social phenomenon (indigenisation) both of which have a significant historical background, it means that some of descriptive details may need to be traced back to the past. As a result, some of the literature used is dated, yet classical and bore a significant historical account that required inclusion in the study.
- The discussion on the analysis of medical and socio-economic aspects of DS is mostly based on articles variously published by Christianson and Modell. This is because they are the main scholarly contributors and leading figures in the field in South Africa and Africa as a whole. This may be a limiting factor in the field of medical genetics and genetic counselling in Africa and, by implication, social work in health care in particular. The field is relatively new and developing, and it is also characterised by a very slow pace and limited scope of scholarly publications.

- Linked to the above point, there is also a limitation related to the lack of up-to-date statistics, particularly with regard to incidences and prevalence of DS in South Africa and its socio-economic impact. Where the statistics are available, it is mostly dated.

## **1.9 Structure of the research report**

### Chapter 1: General introduction

This chapter provides an introduction to the research report. It gives a general overview of the study and introduces the problem of DS amongst African families, and the need for the indigenization of social work practice to respond appropriately to issues arising from the challenge of raising a child with DS. The research questions, aim and objectives of the study, the philosophical grounding and theoretical perspectives used, as well as ethical considerations and limitations of the study, are also introduced in the chapter. The chapter is concluded with an overview of the chapters that are contained in the whole research report.

### Chapter 2: The research design and methodology

This chapter deals with the research methodology used in the study and also outlines how the qualitative research process unfolded. The overall nature of the present study that has a qualitative, phenomenological design with an interpretive paradigm is described in detail. The chapter further presents the empirical processes, namely the collection, analysis and verification of data.

### Chapter 3: The historical overview of social work and the need for indigenisation

This chapter gives a historical overview of social work globally (United States of America & Europe) and locally (South Africa), provides a description of interconnecting events and wider forces that shaped social work. The chapter is concluded by highlighting the need for indigenisation on the basis of the historical account given.

### Chapter 4: The nature of social work practice with African families raising children with DS

This chapter deals with the nature of social work practice in South Africa, the theoretical perspectives and approaches used by social workers as well as their historical origin. The chapter also provides an extensive literature review on the African family, its structure and functioning, culture and tradition, as well as documented experiences, challenges, and needs of African families when dealing with child rearing, disabilities, with particular reference to mental retardation and children with DS.

#### Chapter 5: Presentation and analysis of research findings

This chapter deals with the presentation and analysis of data. The conclusions were drawn based on the research findings and show the need for social work practice guidelines for assisting families raising children with DS.

#### Chapter 6: The practice guidelines

The chapter presents the proposed indigenous social work practice guidelines for assisting families raising children with DS.

#### Chapter 7: Summary of the research process

The chapter consists of the summary of the research process, conclusions and recommendations.

The following chapter outlines the research methodology that was used in this study and provides adequate detail as to how it was applied.

## **CHAPTER TWO**

### **RESEARCH METHODOLOGY**

This chapter presents the research methodology that was used in the execution of this study.

#### **2.1 Introduction**

In their definition of methodology, Grove et al. (2013:488) highlight that the concept of methodology covers the design, setting, sample, methodological limitations, the data collection and analysis techniques in a study. Likewise, Kaplan (cited in Carter and Little, 2007:1318) defines research methodology as the description, the explanation and the justification of methods used in the study. In view of the above descriptions, the researcher deduced that the research methodology constituted the study itself, and how it unfolded, including how the participants were selected, data have been collected, analysed, and interpreted. This process involves a detailed description of processes that were followed in executing the study. The following sections give a detailed description of the research approach, design and methods used to select the sample, data collection, data analysis and verification.

#### **2.2 The research approach**

The researcher utilised a qualitative research approach. Grove et al. (2013:705) explain the qualitative research approach as a systematic, interactive, subjective approach used to describe life experiences and to give them meaning. For further clarification, the aforementioned authors further state that this approach is mostly associated with words, language and experiences rather than measurement, statistics and numerical figures. On the other hand, Creswell (2013:201) highlights several characteristics underpinning qualitative research as including, amongst other things: the view that the research takes place in the natural setting; relies on the researcher as an instrument for data collection; employs multiple methods of data collection; is inductive; is based on participants' meaning; is emergent; often involves the use of a theoretical lens; is interpretive and holistic.

On the basis of the above theoretical explanations, the researcher deduced that qualitative research is indeed systematic because it involved a series of logical pre-determined steps for collecting and analysing data as well as the interpretation and dissemination of results. It is not an event, but a systematic process. The researcher further asserts that the qualitative research approach is interactive in the sense that the researcher joins hands together with the research participants in order to explore and/or construct social reality associated with the experiences of families that have to deal with DS.

The researcher advances that the interactive nature of qualitative research finds expression in its subjective nature. The researcher further concurs fully that qualitative research is subjective and, consequently, the participants' own point of view was crucial in this study. The researcher tapped into the reality of research participants which is taken to be subjective and variable across individuals, hence Creswell's (2013:202) assertion that qualitative research is inductive. The main purpose of the researcher was thus, to have an in-depth understanding of the different views regarding the reality as seen by participants. Most importantly, the researcher acknowledged the significance of life experiences and meanings attached to those experiences while considering the context which is the natural setting of the experience.

In determining the rationale for choosing a qualitative research approach, the researcher referred back to the main aim of the study which involved developing an in-depth understanding of the experiences and coping mechanisms of African families raising children with DS as well as the perceptions of social workers who provided services to such families. A qualitative approach with its interactive and subjective nature provided ample opportunities for the development of an in-depth understanding. The flexibility imbedded within the qualitative approach allowed for a dynamic focus on individual experiences of the phenomenon under discussion as well as further exploration of commonalities and variations amongst individuals.

## **2.3 The research design**

A research design can be defined as a plan for conducting the study (Creswell, 2013: 49). A similar view has been expressed by Babbie and Mouton (2009:55) earlier on when they explained a research design as being a plan or blueprint for how one intends conducting a study. For Fouché and Delport (2011:64), a research design is a plan to guide the researcher in collecting, analysing and interpreting observed and collected data. In line with the spirit of the research questions, aims and objectives outlined earlier, the researcher adopted a phenomenological, exploratory, descriptive and contextual research design. The above designs were followed from the premise of an interpretive paradigm which is based on the belief that multiple realities exist for interpretation. In this case, the multiple realities of African families were explored and interpreted. The following section gives details on how each of the selected research design was employed:

### **2.3.1 Phenomenological research**

Phenomenological research refers to any qualitative description of a phenomenon as seen through the eyes of the people who experienced it at first hand (Fouché & Delport, 2011:317). While, Grove et al. (2013:703) defined phenomenological designs as inductive, descriptive qualitative methodologies describing experiences as lived by the research participants. The study sought to unearth contextual lived experiences of African families raising children with DS so as to inform social work practice. The focus on lived experiences of African families has been instrumental in assisting the researcher to uncover real experiences from the point of view of the people experiencing instead of using external explanatory tools that look at a situation from afar. The use of phenomenology enabled the researcher to learn from the participants as both subjects and scientists of their own experiences. This research strategy yielded rich and in-depth insights including how they dealt with, and the subjective meanings attached to, such experiences.

### **2.3.2 Exploratory research**

According to Grove et al. (2013:370) explorative research is conducted to gain new insights, discover new ideas and/or increase knowledge of a particular phenomenon. Put differently, Fouché and De Vos (2011:318) postulate that exploratory research

focuses on the “how” and the “why” questions. Furthermore, Neuman (2006:23) maintains that the primary purpose of exploratory research is “to examine a little understood phenomenon to develop preliminary ideas and move towards a refined research question by focusing on the “WHAT” question. As argued by Babbie and Mouton (2009:191) exploratory research is often undertaken to satisfy the researcher’s curiosity and the desire for better understanding. The research study undertaken sought to explore a phenomenon, deemed less understood, which is, the African families raising children with DS, their experiences and coping mechanisms as well as suggestions for culturally appropriate social work interventions as a vehicle to arrive at the destination of practice guidelines for appropriate social work interventions to these client systems.

The researcher reviewed numerous studies conducted in several countries perceived to be more inclined to a different cultural orientation than that of the Eurocentric and western individualistic cultures. The reviews revealed that countries perceived to be following a more collective cultural orientation such as Japan, China, Singapore and India, are amongst those that have undertaken indigenisation studies in social work practice (Osei-Hwedie, 2011:138; Gray & Coetes, 2008:3; Gray, 2005:231; Yip, 2005:593; Cheung & Liu, 2004:56; Tsang & Yan, 2001:63). In contrast, very little has been done in Africa, particularly in South Africa, to address the need for the indigenisation of social work practice. This situation thus called for initial exploratory studies that would assist in determining the baseline for further studies towards the development of indigenous practice models in South Africa. The present study managed to achieve the objective of determining the basis for indigenous social work practice with African families raising children with DS by developing indigenous practice guidelines for social workers practising in this field. This provides an important starting point that would serve as a precursor for further follow-up studies that might attempt to develop new indigenous theories and models for practice.

### 2.3.3 Descriptive research

On the one hand, Grove et al. (2013:632) proffer an explanation that descriptive research is a research strategy that provides an accurate portrayal or account of the characteristics of a particular individual, event or a group in a real life situation for the purpose of discovering new meaning. Neuman (2006:35), on the other hand, describes

the purpose of descriptive research as being “to paint a picture using words or numbers and to present a profile, a classification of types, or an outline of steps to answer questions such as whom, when and how”. In this study, the researcher sought to paint a picture using the text of what the nature of experiences and coping mechanisms of African families are in relation to raising children with DS, as well as a picture of the perceptions of social workers in this regard. A detailed account of the characteristics of the research participants and their experiences raising children with DS (the phenomenon being studied) in a real life situation is provided with the findings to allow for the discovery of meaning for indigenisation of social work practice. All of the above provided for the descriptive nature of the study as it allowed the researcher to gain an in-depth insight into the phenomenon studied. The researcher then proceeded to describe it in detail, including the various dimensions and dynamics of the phenomenon that emerge. As indicated earlier in the motivation for an exploratory study, very little is known, or has been studied, in relation to the indigenisation of social work with African families raising children with DS. As such, the study contributed towards closing the knowledge gap in this regard by describing the actual characteristics and experiences of African families raising children with DS.

#### 2.3.4 Contextual research

The researcher viewed the context of the study as a critical and integral part of qualitative research. By their nature, therefore, qualitative studies are contextual (Grove et al., 2013:632). Furthermore Grove et al. (2013:632) articulate that contextual studies focus on specific events in “naturalistic settings”, while according to Hennink et al. (2011:288), the context of the participants must be reflected throughout the research process. The aforementioned authors further highlight specific contexts that are crucial, including the subject context, and the theoretical, cultural, physical and methodological as well as issue context.

This study was indeed contextual and observed all the contextual dimensions as postulated by Hennink et al. (2011:288). The contextual dimensions included amongst others: the African families raising a child with DS context (nature of the family, challenges and coping mechanisms), and the context of social work assistance to the African families raising a child with DS context. Through an in-depth exploration of the above contexts, the researcher was able to arrive at the destination of practice

guidelines for indigenous social work intervention for these client systems. The notion of context was important in the sense that the study sought to explore the significance of the context in determining how social work practice with families raising children with DS could be indigenised. It is based on the belief that social work practised in different contexts cannot be delivered the same way because contextual factors differ and that related contextual influences need to be understood and considered. The researcher decided on specific theoretical lenses, consistent with the research approach and paradigms followed, to enable the interpretation of meaning in the study.

## **2.4 Research methods**

The following section presents a discussion on the research methods utilised in the study. According to Carter and Little (2007:1318), research methods involve practical activities proposed for the study including sampling, data collection, management of data, analysis and reporting.

### **2.4.1 Population, sampling and sampling techniques**

The phrase 'research population' refers to "the aggregation of the elements from which the sample is actually selected" (Rubin & Babbie, 2013:327). This refers to the entire universe of people, objects or events of concern to the study from which a sample is drawn. The study under discussion was conducted in Gauteng, Limpopo, Mpumalanga and the North-West Provinces. The research population consisted of two categories. Firstly, it included African families raising a child with DS older than a year residing in one of the four provinces mentioned above. This category was further divided into two groups: one consisting of members of the family interviewed together at their homes and the other category consisting of parents and guardians of the children with DS who were involved in a focus group discussion.

The second category included social workers providing professional social work services to the families in their respective areas of residence, in the above mentioned provinces. The decision to focus on the four provinces listed above stemmed from the fact that the National Health Laboratory Services (NHLS) in Johannesburg provides pre- and post-natal testing for DS, and the Down Syndrome Association (DSA) in

Pretoria conducts outreach programmes in all of the four provinces. A letter (see Addendum E) requesting permission and access to families of children with DS was sent to the Down Syndrome Association which, in turn, provided details of individuals and families of children with DS as well as existing support groups in the four provinces mentioned above.

According to Grove et al. (2013:701), sampling refers to the “procedures used to select a sample to represent the population”. The sampling method used was ‘purposive’ owing to the fact that the researcher was looking for specific attributes in participants as argued by Neuman (2006:202). Additionally, the ‘snowball’ or ‘network’ sampling technique was used to get the identified participants to assist in locating others. Grove et al. (2013:701) argue that snowball or network sampling refers to “a non-probability method that takes advantage of social networks and the fact that friends tend to hold characteristics in common”. This means that those participants identified through purposive sampling were asked to assist in locating others with similar characteristics.

The reason for a combination of purposive and snowball or network recruitment was that, as stated by Hennink et al. (2011:84) in a qualitative study “the depth of information and variation of experience are of interest”. The above therefore, required that the researcher select participants with specific characteristics that would enable him to be able to have adequate insights to inform the research topic. A total of five (5) focus groups were facilitated and about twenty seven (27) family interviews as well as twenty (20) interviews with social workers conducted. The size of the sample was based on the point of data saturation.

The African families selected purposefully or through snowballing, had received some form of service or other from a qualified social worker. The social work services were mainly rendered to the biological parents of the child with DS, that is one (mother) or in some cases two members (couple) of the family with an insignificant number of family interventions (family visits by social workers). The participants were recruited from existing DS support groups affiliated to the DSA in the four provinces identified for inclusion in the study and consisted of mainly the biological parents (mothers) or alternative primary care givers who were mainly grandmothers. A request to interview the African families of children with DS was submitted to the DSA at the national level.

The first category of members of the African families was divided into two; that is, the family interview and the focus group discussions. The number of focus group discussions was determined at the point of saturation after the fifth (5<sup>th</sup>) group discussion was facilitated. The five focus group discussions were conducted in three provinces namely; one focus group of eight (8) members in Limpopo (Tzaneen); two focus groups of twelve (12) and five (5) respectively in the North West province (Potchefstroom and Mafikeng respectively); and another two focus groups of seven (7) and twelve (12) respectively in Gauteng (Coronation and Natalspruit hospitals). A total headcount of forty four (44) participants participated in the five (5) focus group discussion sessions.

The selection criteria for the family and focus group participants were:

- One must be a member of an African family that raises a child with DS as defined for the purposes of this research (biological parents, sibling, aunt, cousin, uncle) and may or may not be living with the child;
- The child with DS must have a confirmed diagnosis of DS and be more than a year old given that the research focused on their experiences of raising the child with DS;
- Participants had to be residing in one of the four provinces identified for the study;

The second category of interviews was with the social workers. The social workers interviewed came from the four provinces mentioned above. Two social workers interviewed were from Limpopo province; thirteen (13) social workers from the North-West province; two (2) from Gauteng; and three (3) were from Mpumalanga province. Similar to the sampling techniques used for African families, the researcher used purposive and snowball sampling procedures to select participants in this second category made up of social workers. The North-West province happened to have more social workers available and easily accessible through snowballing. The size of the sample was also based on the point of data saturation.

The selection criteria for social workers were as follows:

- The social workers selected were those who had provided a service to a member or a group of members of the African families raising children with DS;
- Registered with the South African Council for Social Service Professions (SACSSP); and
- Employed either by government or a hospital for more than a year. This was important given the fact that the researcher was interested in exploring paradigms and worldviews underpinning social work practice to the specific category of people (families raising a child with DS).
- Furthermore, social workers were required to have at least one year experience, given that the research was interested in their work experience.

#### 2.4.2 Methods of data collection

According to Grove et al. (2013:373), data gathering refers to the precise, systematic gathering of information relevant to sub-problems, using methods such as interviews, participant observation, focus group discussion, narratives and case histories. For the purposes of this study, semi-structured interviews were conducted using three separate data collection tools. There were two different data collection tools used for the first category of interviews involving members of the African families raising children with DS. One of them being a list of focus group prompts (Addendum G) used for the focus group discussions and another one being an interview guide (Addendum F1) for family interviews. The second category of interviews was conducted with the social workers and a separate interview guide (Addendum F2) was developed and used for the interviews with social workers. All the interviews were digitally recorded and transcribed.

The semi-structured interview, as a method of data collection, involves a process in which the interviewer compiles a list of issues to be addressed and questions to be answered by the interviewee with a degree of flexibility with regard to the order in which the topics will be covered as well as allowing the interviewee to speak more widely on issues raised (Denscombe, 2007:176). It is noteworthy that Hennink et al. (2011:109) concur with the above explanation of semi-structured interviews and they emphasise further the interactive nature of semi-structured interviews. They argue that semi-structured interviews can be summed up as a “conversation with a purpose”

wherein the researcher uses questions contained in a semi-structured interview-guide to gain insight into the aspects inherent in the topic under discussion.

Semi-structured interviews, guided by an interview-guide, were used to collect data (see Addendum F1&2). The interview guide contained a list of pre-determined issues to be covered in the semi-structured interview. This type of a data collection tool was used for the interviews with families and social workers. The second data collection method used in this study was the focus group discussions using focus group prompts (Addendum G). The researcher made use of existing DS support groups run by the DSA. According to Morgan (2008:29), a focus group as a data collection method refers to group discussions of six to twelve persons organised to explore a specific set of issues such as views and experiences of people around a particular issue. According to Morgan (2008:29), a 'moderator' facilitates the group discussions. Similarly in this study, the researcher served as moderator and facilitated the discussions in the focus groups. The idea of the group being focused stemmed from the fact that it involved some kind of collective activity in a sense that members shared a similar type of experience.

The most important factor that distinguishes a focus group as a data collection tool from other forms of group interviews is the use of group interaction as research data. The choice of the above data collection tool was motivated by the fact that the study was aimed at uncovering personal identity, experiences and coping mechanisms. Focus groups are known to be very useful in investigating such issues as people's thoughts, but, most importantly, they excel at uncovering why participants think as they do (Simpson & Sambuko, 2011:72; Sturgeon & Keet, 2010:157). This is because participants do not only share with the group what their views and experiences are, but they are often encouraged by other group members to explain the reasons for holding such views (Simpson & Sambuko, 2011:73). Furthermore, Simpson and Sambuko (2011:73) also mentioned yet another advantage of using a focus group as a research tool: the fact that participants can react to and build on the responses of other group members. It provides data from a group of people more quickly than interviewing individuals. This implies that focus groups are less costly than individual interviews. The researcher allowed the participants to speak for themselves with minimal interference through employing low levels of involvement in facilitating the focus group

discussion. The general prompts or focus group prompts were used to ensure that the interview maintains a focus and that the major themes of interest are explored (see Addendum G).

According to Morgan (2008:29), the most preferred approach in facilitating a focus group discussion is nondirective, which he aptly calls a “self-managed group”. It is highly recommended by several scholars that low levels of moderator involvement should be adhered to in exploratory research. Such an approach appeared to be appropriate for this study on the basis that the aim of the researcher was to learn something from the participants. The researcher thus found it best to let the participants speak for themselves with minimal interference through employing low levels of involvement.

Below are the focus group prompts that were used to facilitate the discussion:

- Let us have a discussion about your families...
- Let us talk about your experiences of caring for a child with DS as a family...
- Let us talk about your coping mechanisms...
- Please let us talk about the services you received from a social worker...
- Please share your suggestions about how you would like to be assisted by social workers within your cultural context.

#### 2.4.3 Preparation for data collection

The following procedures were followed in recruiting and preparing participants for data collection:

The researcher sought approval for the proposed study as well as ethical clearance from the Department of Social Work’s Research and Ethics Committee, as already mentioned earlier. Once the approval and ethical clearance was granted, the researcher contacted gatekeepers to the research population and sought permission to enter the research site and interview selected participants. In this study, the main gatekeepers included the DSA’s national office, its provincial offices in the identified

provinces, and employer organisations for the selected social workers included in the study.

Written requests were submitted to the various gatekeepers, followed by face-to-face meetings with the respective gatekeepers to introduce the researcher officially and explain the purpose of the study. Once all the formalities were concluded with the gatekeepers, the process of purposive sampling began. In cases where interviews were to be carried out in organisational premises, the researcher scheduled times with the respective organisations to orientate himself to the organisational environment and culture to ensure that pertinent organisational norms and values are observed during the course of the interviews so as to prevent unnecessary disruptions that might have resulted from any violation of organisational rules and procedures.

In making contacts with potential participants, the researcher adopted the guidelines of Lloyd, Kalsy and Gatherer (2007:68) as stated below:

- The researcher explained the purpose of the study;
- The researcher clarified the possible value of the study;
- The researcher explained to the potential participants why they, in particular, were chosen to participate in the study;
- The researcher contracted the participants about follow-up interviews;
- The researcher clarified and negotiated the venue for the research interview;
- The researcher explained the duration of the interview and the fact that the interview would be digitally recorded with their consent;
- The prospective participants were informed that, after the interview, the researcher would transcribe the recorded interview and that their identity would not be revealed; and
- Ethical issues were discussed and clarified to them, as well as how they will be applied in the study.

The researcher began by making contact with the selected participants. The initial contact served to introduce the researcher and the purpose of the study. The research process was explained in detail including ethical issues, the researcher's obligations, and his expectations. At the end of the briefing, the potential participants were given an option of either proceeding or opting out of the study. When they chose to participate,

the researcher then asked them also to assist in identifying others with similar characteristics and then followed a similar process with those so identified. All interested potential participants were taken through the consent form and the process of signing was facilitated (see addendum B & C). The actual data collection process followed in a form of semi-structured interviews with African families, social workers as well as focus group discussions.

#### 2.4.4 The pilot-testing of data collection tools

Pilot-testing the data collection tools is described by to Grove et al. (2013:703) as involving the process of subjecting the tools to a smaller version of a proposed study conducted to develop or refine the data collection tools. It was the researcher's view that the pilot-testing of data collection tools served as a dry-run of data collection tools carried out before the actual study in order to identify shortfalls so as to modify the tools accordingly to ensure and maximise their effectiveness and efficiency. Kumar (2013:305) expresses similar sentiments and points out that the outcomes of pilot-testing are used to determine whether or not modifications to the piloted offerings are required, or whether it can be rolled out as it is.

For the purposes of this study, the researcher selected a small sample with a total headcount of ten (10) participants from the same research population of the study and interviewed them as part of pilot testing of the data collection tools. All three data collection tools were subjected to pilot testing in a hospital in Gauteng within the Tshwane region (George Mukhari hospital). One family of a child with DS comprising three (3) family members was interviewed using the interview guide for the families; followed by pilot testing of the focus group prompts with a small group of five (5) mothers of children with DS and the interview guide for social workers was pilot tested with two (2) individual interviews with social workers at the hospital. As part of the pilot-testing process, semi-structured interviews with the family and two social workers as well as focus group discussions were conducted and digitally-recorded to enable the researcher to check the accuracy and trustworthiness of data collection tools. The participants who participated in the pilot-testing process did not form part of the main study. The interviews were then analysed. The researcher did not make any

methodological changes because the findings coming out of the pilot-testing of data collection tools did not point to a need to change anything.

#### 2.4.5 Methods of data analysis

Once the process of data collection was concluded, the collected data was subjected to an analysis process that involved interpretation of findings in order to gain a better understanding of the phenomenon. According to Creswell (2013:183), data analysis as a process involves making sense of collected data. It is an on-going process of analytical reflection. Allied to this definition, Fouché and Delport (2011:333) assert that data analysis is the process of bringing order, structure and meaning to the mass of collected data. The qualitative data was analysed following the methods of qualitative data analysis adapted from Terre Blanche et al. (2006:33). The five steps of the data analysis process were preceded by the following step:

The researcher subjected the research data to a systematic process of analysis with the aim of identifying common themes in the participants' responses. The interviews were conducted in seven ethnic languages that were voice recorded. The researcher, with the help of his research assistant, listened to the voice recording multiple times. As a way of quality control, the researcher and the assistant checked each other's understanding to prevent possible misrepresentations of the participants' responses. The voice records were then transcribed into written text. Once the above process was completed, the transcriptions were then analysed following the five steps in the data analysis process by Terre Blanche et al. (2006:33).

The first step is called familiarisation and immersion, which when put in simpler terms, means reading through, making notes, drawing diagrams and brainstorming to get an overview picture of the data. The researcher read the transcriptions several times, noting pieces of commonly occurring text and arranging the text in a particular order using a mind map. The mind map helped the researcher to organise commonly occurring text and group it in a particular order with related text. This was used later in the second step to generate themes. For example, all text related to the identity of the family was grouped together and all text related to the disclosure of the child's diagnosis was also grouped together.

The second step is known as inducing themes. Inducing themes means to infer general rules or classes from specific instances in a bottom-up approach. In this step the researcher looked at the material and worked out what the organising principles were underlying the material, which is contrary to a top-down approach where one uses ready-made categories and simply looks for instances fitting such categories. This is also known as 'internal locus of insinuation' (Sithole, 2016:26). This means that inferences are made and themes generated and emerge from within contrary to them being super-imposed and generated from without. It was in step two that the researcher searched and identified the explicit and implicit meanings attributed to the phenomenon of the experiences of African families raising children with DS and the social workers supporting these families.

Step two further involved re-articulating what was stated openly as well as what was implied from a psychological perspective. Here segments of statements were grouped into themes. Through this process, four themes emerged in line with the aims and objectives of the study as outlined in chapter one. The main themes were further broken down into two to three sub-themes, depending on the issues coming out of the transcriptions.

Step three is called coding. Coding means marking different sections of data as being instances of, or relevant to, one or more of the researcher's themes. The researcher used coloured marker pens interchangeably to highlight pieces of text. When coding, the researcher organised the raw data into conceptual categories and created themes or concepts, which he used to analyse research data. Through the use of coding, the researcher managed to reduce huge amounts of raw data into smaller manageable units.

Step four is known as elaboration. Elaboration means putting information in a linear sequence and the fifth and final step is data interpretation and checking, which involved going back to all the steps to make sense of the data and checking for the misplacement of certain texts. Step four and five were done jointly as they are inter-related. The researcher went back to the different themes and categories of data and substantiated them further through linking with the literature control and giving

meaningful interpretations as per extrapolation. The data was then double checked for errors of interpretations and gaps. Where errors were picked up and gaps identified, they were duly corrected. The fifth step culminated in the construction of a final composite of analysed data with interpretations flowing into conclusions and recommendations. Here the researcher used the various meanings identified to develop an overall description of the experiences of African families raising children with DS, as well as the opinions of social workers regarding congruence between the lived experiences of African families and social work. This was followed by the development of the indigenised social work practice guidelines for assisting African families raising children with DS.

#### 2.4.6 Methods of data verification

When dealing with qualitative data it is important to establish the level of confidence in relation to the extent to which it represents the genuine meanings of participants. This process is called data verification, and it is aimed at establishing the trustworthiness of data. In the interest of both clarity and simplicity, Streubert, Speziale and Carpenter (2003:364) describe trustworthiness as “establishing the validity and reliability of qualitative research”. Contrary to the usage of the term ‘validity’ in quantitative data, qualitative researchers prefer to use the term ‘credibility’. According to Lietz, Langer and Furman (2006:443), trustworthiness is established when the findings describe as closely as possible the meanings described by the participants. This led Lietz et al. (2006:444) to state that trustworthiness can be achieved through the application of reflexivity, audit trail, triangulation, peer debriefing, member-checking, and prolonged engagement. On the other hand, Guba’s model (in Krefting 1991:214) of ensuring the trustworthiness of qualitative data talks about the four characteristics to ensure trustworthiness as follows: truth-value, applicability, consistency and neutrality. For the purposes of this study, trustworthiness was assessed using Guba’s model as described in Krefting (1991:214) using the criteria of truth-value, applicability, consistency and neutrality.

- Truth-value

The truth-value is obtained through the discovery of human experiences as they are lived and experienced by participants. Krefting (1991:215) describes truth-value as

subject oriented and not defined *a priori* by the researcher. It can be obtained through a prolonged and varied field of experience, time sampling, reflexivity, triangulation, member checking, peer examination, establishing the research integrity of the researcher, and referential adequacy strategies.

The researcher assessed truth-value by allowing enough time for interviews, by establishing rapport, building trust, encouraging open conversation without fear and discrimination, and conveying to participants how meaningful their contribution to the process would be. This allowed the participants to share their true experiences freely. The researcher triangulated different data sources to attain truth value as indicated when data collection and analysis were discussed.

Triangulation is described by Krefting (1991:219) as the comparison of multiple perspectives by using different methods of data collection. Through triangulation, the researcher was able to leverage the richness of text. The researcher combined two data collection tools and methods that are semi-structured interview facilitated through guides, for interviews with African families raising children with DS and group prompts for focus group discussions with primary care-givers and/or parents of children with DS. The researcher compared and checked for congruence between what was said among the different data collection tools and found that there was consistency between the two data collection tools.

- Applicability

Applicability is the degree to which the findings can be applied to other contexts and settings (Krefting, 1991:216). This criterion can be addressed, according to Krefting (1991:216), through the presentation of sufficient descriptive data that may allow comparison. The researcher ensured that in-depth and dense descriptions of participants and their experiences are presented as far as possible, including details of the context, process and settings in order to enable the transferability of findings. The researcher, however, acknowledges the fact that qualitative data is not easily transferable, and was in fact, not meant for generalisation.

- Consistency

Consistency of data refers to “whether the findings would be consistent if the enquiry was replicated with the same subjects or in a similar context” (Krefting, 1991:216). Consistency was established through the strategy of dependability which refers to a variability that can be ascribed to the identified sources. This means that, if the study is repeated in a similar context with the same participants, the findings will be consistent. The researcher used a code-recode procedure of data during the analysis processes. After coding a segment of the data, the researcher would wait for about two weeks and then return to recode the same data and compare results for consistency.

- **Neutrality**

The last criterion of neutrality or conformity is defined as the freedom from bias in the research procedures and results (Krefting, 1991:216). One can safely argue that the first criterion of truth-value and applicability automatically addresses this criterion. Despite the above, the researcher relied on reflexivity wherein he used his own experiences to understand the data and personal meanings so that he is able to bracket out his own meanings from the participants’ meanings.

## **2.5 Summary of the chapter**

This chapter dealt with the research design and methodology used in the process of executing this research project. It described the overall nature of the study as qualitative, phenomenological research with an interpretive paradigm. The chapter also described the empirical processes, namely, the collection and analysis of data from participants. As discussed, the use of a qualitative data analysis to make sense of the identity and experiences of African families raising children with DS and the views of social workers regarding the level of congruence between the services they render and the nature and experiences of African families was followed. The triangulation of data collection tools and methods (focus groups and family interviews as well as individual social workers interviews) has significantly enriched data collection and its outcomes. This resulted in a well-rounded and comprehensive coverage of the unit of analysis. As expected in qualitative research, the researcher ensured that measures were in place to establish ‘trustworthiness’, which is the level of confidence in collected data in relation to the extent to which it represented the genuine meanings of participants.

The following chapter addresses an overview of historical and contemporary social work and the need for indigenisation.

## **CHAPTER THREE**

### **THE HISTORICAL AND CONTEMPORARY OVERVIEW OF SOCIAL WORK AS WELL AS THE NEED FOR INDIGENISATION**

#### **3.1 Introduction**

This chapter examines the origin and development of social work internationally and in South Africa. The discussion culminates in a review of contemporary social work and the need for indigenization of social work practice. The task of conducting a historical analysis of social work was complicated by the fact that competing histories exist together with dominant narratives that may carry different meanings depending on the ideological position of the examiner. However, it is clear from the analysis of literature that individualist and liberal discourses occupy the space of dominant narratives and rhetoric in social work (Worden, 2008:73; Tsotsi, 2000:35). It is on the basis of the above situation that Smith (2008:374) proclaimed that "...unless there is critical engagement with the stark past and present realities of structural and social relations of power, privilege, inequality and oppression, social workers in South Africa will deserve the past label of being upholders of the status quo". Indeed, it is the researcher's contention that in examining the history of social work we need to appreciate the relationship between events and choices made in the context of the burden of history, especially political inequality in terms social work resources, capacity and ideological orientation.

Thus, an objective assessment of the history of social work should enable us to uncover the unspoken socio-political and economic forces that shaped its development from inception to date. Similar to the approach taken by Smith (2008:375), the researcher undertook a historical materialist perspective in examining the history of social work locating the origins of social work within the dynamics of the modern capitalist system characterized by the conditions of poverty and social conflict. As argued by Hill (2009:616), the dialectical-historical investigation, as a perspective to counter the fiction of a purely historical record of 'progress' and freedom of choice, devoid of any contextual interpretation, allows for probing the impact of these conflicts and forces on the development and shaping of social work.

In analysing the history of social work, one realises that for many decades, its knowledge base and associated technologies have been a monopoly of the global North (Europe) and North America (USA) (Gray, Kreitzer & Mupendziswa, 2014:103; Rankopo & Osei-Hwedie, 2011:140; Gray, Coates & Yellow-Bird, 2008:6; Yip, 2006:48; Gray and Allegritti, 2002:328; Nimmagadda & Balgopal, 2000:10; Midgley, 1981:25). The Anglo-American domination of social work has been underscored and criticised by many social work scholars over the years (Gray et al., 2014:103; Brydon, 2011:160; Rankopo & Osei-Hwedie, 2011:141; Gray, 2010:120; Gray et al., 2008:7; Askeland & Payne, 2006:736; Gray & Fook, 2004:630; Atal, 1981:190; Midgley, 1981:25).

Seemingly, the Anglo-American domination has not limited its scope to social work, but it has also engulfed the social sciences broadly. Indeed, Boroujerdi, one prominent proponent of indigenisation in the social sciences, characterised the Eurocentric domination of social sciences as 'intellectual colonisation' (Boroujerdi, 2002:40), while in social work, the Anglo-American domination of the social work profession in third-world countries has been characterised as 'professional imperialism' by Midgley (1981:26). Echoing popular sentiments of fellow proponents of indigenisation in the social sciences, Boroujerdi (2002:41) argued that the Eurocentric philosophy and its associated principles of objective reasoning, humanism, the idea of progress, culture transcending knowledge and the dualism between religion and science represent an antidote of alternative indigenous cultural traditions, history and culture that should foreground indigenous social sciences. Similarly, in social work, proponents of indigenisation such as Gray et al. (2014:103), Rankopo and Osei-Hwedie (2011:141), Gray et al. (2008:7), Yip (2006:48); Gray and Allegritti (2002:328), Nimmagadda and Balgopal (2000:10) and Midgley (1981:25) argued that social work methods, theories and techniques parachuted from the global north and west are irrelevant and ineffective in African and Asian contexts. They argue that alternative theories and concepts based on indigenous cultural orientations and worldviews should be developed to build indigenous social work.

However, several critiques of the indigenisation thesis have emerged as indicated by Pellebon (2007:173), Yunong and Xiong (2012:43), pointing to lack of empirical evidence and scientific rigour required for alternative indigenous conceptualisations to qualify as valid theory that can be added to the social work body of knowledge. Based on this, they proceed to argue that it is an inherent professional requirement for social

workers to appreciate different ways of knowing to understand, practice and conduct research in various local contexts, implying that indigenisation is not a new phenomenon. The iniquitous criticism of indigenisation carries in itself a blindingly obvious contradiction in that it uses the self-imposed supremacy of western paradigms to define and validate knowledge as well as impose set universalised standards and norms against which any knowledge is authenticated. This, while ignoring significant contextual realities that produce and shape knowledge. Such tendencies unwittingly perpetuate Anglo-American hegemony and biases against alternative ways of knowing. Despite the above criticism, the indigenisation movement in social work is growing, resulting in polarisation between its proponents and antagonists whose vested interests could be said to be residing in the status quo.

In the midst of positive progress in indigenisation are attempts within the domain of international social work to universalise social work knowledge. This refers to the spreading of the profession of social work across the world as a uniform system (Gray & Fook, 2004:629). The scholarship in social work unanimously agree that international social work is emerging as a domain with a universalist outlook (Schmid & Patel, 2014:3; Brydon, 2011:160; Askeland & Payne, 2006:739; Gray & Fook, 2004:629; Healy, 2001:25; Midgley, 2001:46;). However, while there is agreement about the emergence of international social work as a domain and its universalist mode, the important and unavoidable question remains unanswered: 'whose knowledge is it?' Hence, the admission that the manner in which global and local ideas interacts with one another in the sphere of international social work is not clear (Schmid & Patel, 2014:3). Further complications emanate from the observation made by Schmid and Patel (2014:4) that the domain of international social work has developed in tandem with increasing globalisation.

The researcher maintains that internationalisation and globalisation are mutually beneficial and reciprocal processes requiring closer and critical examination. Similar sentiments about the effects of globalisation on social work are echoed by Askeland and Payne (2006:138) who argue that globalization has become a major driver of internationalisation and homogenisation of social work education. In this regard, Askeland and Payne (2006:138) advanced a firm position on the impact of globalising forces by stressing that globalisation in social work education have an oppressive impact on local cultures, despite there being an opportunity for greater awareness and

interaction which should ideally breed greater heterogenisation. Some authors have characterised the iniquitous relationship between international social work and previously ignored indigenous social work as an ethical imperative (Gray et al., 2014:110), while others invoked the social justice and human rights principle (Brydon, 2011:160; Sewpaul, 2006:213; Gray & Fook, 2004:630). It was on the basis of the paradox described above that Gray (2005:235) highlighted earlier on that international social work is on the horns of a three-pronged dilemma arising from the contradictory processes surrounding indigenisation, universalism and imperialism.

### **3.2 The landscape of international social work**

The peculiarity of international social work is such that there is no consensus amongst scholars in social work about its definition (Brydon, 2011:163; Gray & Fook, 2004:641). The perspectives put forward vary and range from those that argue that what is touted as 'universal social work' is in fact 'western social work' (Brydon, 2011:163; Askeland & Payne, 2006:740; Yip, 2006:53; Midgley, 2001:48; 1981:26), and others even arguing that it is elusive as there is no such a thing as international social work (Ife, 2000:10). As Midgley (2001:46) puts it, social workers are sharply divided on a number of important issues such as: the nature of international social work; the profession's commitment to internationalizing social work education and practice; the universality of social work values; internationalism as a desirable normative position; and on the nature of social work itself.

On the one hand, Askeland and Payne (2006:741) asserted that international social work refers to a globalised, post-colonial world of social work where there is one set of knowledge, skills and values that may usefully be applied in all cultures, while for Gray and Fook (2004:628) international social work is defined as a form of social work that transcends national boundaries and which gives social work a global face such that there are commonalities in theory and practice across widely divergent contexts. On the other hand, Yang (2005:73) postulates that internationalization refers to increased interaction among people and cultures that focuses on mutual understanding and respect, while Healy (2001:26) highlighted that international social work involves action and capacity to act collectively at the international level by social workers.

On the basis of the above definitions, the researcher deduced that there are numerous key characteristics of international social work. They include among others, the

following: action and capacity for action at the international level; transcendence of national boundaries; as well as a focus on commonalities based on mutual understanding and respect. It is vital to underscore the significance of mutual understanding and respect. While not wishing to delve into a discussion on the importance of consensus in the domain of international social work, let it suffice to say that consensus is a necessary prerequisite for the domain.

Indeed, international social work is developing rapidly as a domain (Schmid & Patel, 2014:5; Brydon, 2011:163; Gray & Fook, 2004:640), making it a critical focus of social work scholarship world-wide. The researcher viewed the emergence of international social work as driven by internal factors such as the need to make a contribution to the globalizing body of knowledge and external factors such as the influence of globalisation resulting in the transmission of knowledge from various external to local contexts. Any attempt to understand international social work as a domain should take into consideration the manner in which it has been shaped by a variety of inter-related processes and dynamics without which we will not be able to appreciate the domain in its totality.

Accordingly, the researcher did not assume that the universalist approach adopted by international social work represent a desirable state of affairs. Contrary to the universalist approach, the researcher contended that all forms of social work are indigenous; however particular elements such as some of its values and principles may have a universal appeal. Thus, the rejection of a universalist mode in this chapter was motivated by the fact that the concept of universalization, whose virtues are often extolled in western neo-liberal circles as shown by various scholars (Brydon, 2011:165; Askeland & Payne, 2006:162; Yip, 2006:52; Midgley, 2001:48; 1981:26) resulted in unquestioned assumptions with regard to its embracing of Anglo-American values.

The quest for a universalist mode in international social work has been confirmed by Gray and Fook (2004:640). They argue that the attempt by international social work formations to consolidate global agreements and positions represents universalizing trends within the international social work domain. Amongst other universalising trends, Gray and Fook (2004:640) site attempts to find agreement on an international definition of social work by the International Federation of Social Workers (2000) and the subsequent efforts of the International Association of Schools of Social Work (2002) to institute global qualifying standards for social work education.

To this we can add the adoption of the global agenda for social work and social development commitment to action by the International Federation of Social Workers (IFSW), the International Association of Schools of Social Work (IASSW), and the International Council on Social Welfare (ICSW) in March 2012 as signifying yet another universalising trend in international social work. This is further confirmed by the recent adoption of the new global definition of social work by the IFSW, IASSW and the ICSW in 2014 (Ng, 2014:127). Additionally, Midgley (2008:31) highlighted the fact that the spread of international social work may be attributed to 'international exchange programmes'. However, there are several factors from the outside that influence and shape the trends in international social work. An important one is globalisation.

In the light of the various characteristic features of international social work as outlined in the previous discussion as highlighted by various authors, it would seem that the current state of international social work leaves a lot to be desired. For instance, a mutual understanding and respect for the diversity of perspectives is not fully embraced within the contemporary international social work domain (Yang, 2005:68; Gray & Fook, 2004:635). This has been confirmed by Yip (2006:50) who asserted that international social work merely facilitate the gradual transfer of social work knowledge developed in leading countries such as the USA and the United Kingdom (UK) to diverse contexts across the globe. There is obvious discontent about the state of international social work with regard to its nature, direction and shape as observed earlier by Midgley (2001:46). Midgley (2008:36) eventually expressed great dissatisfaction with international social work describing it as the "new imperialism" which tends to privilege western social sciences and leads to the Americanisation of social science over locally relevant ideas.

Consequently, several social work scholars called for the promotion of diversity rather than the confirmation of hegemony currently prevalent in international social work's universalist mode (Brydon, 2011:162; Askeland & Payne, 2006:741). The researcher notes that attempts were made to consult widely when the global definition of social work was developed. However, it only went as far as developing a definition. The knowledge and theoretical base of social work remains Eurocentric and no attempts were made at an international level to legitimize and mainstream indigenous social work typologies as may exist world-wide. The researcher is of the view that indigenous social work remains marginalised.

Having defined international social work and touched on some of the challenges associated with it, the researcher will now consider various proposals that have been put forward. There is no consensus on the nature, form and structure of international social work and as a result it remains contested and at times elusive (Brydon, 2011:163). However, social work scholars grappling with these challenges proposed several solutions. Some authors proposed cross-cultural awareness (Gray & Allegritti, 2002:330); while others argued for cultural competency and cultural sensitivity as a solution to address cultural influences and biases in practice, research and education (Yunong & Xiong, 2012:48; Lee & Greene, 2011:35). As a critique to cultural sensitive practice, Gray and Allegritti (2002:332) called for cross-cultural practice and emphasized extensive dialogue between cultural groups on principles, ethical norms and appropriate practice towards the achievement of a truly diverse and cross-cultural world.

While the researcher echoes the sentiments of some scholars such as Brydon (2011:162); Askeland and Payne (2006:741); Gray and Allegritti (2002:332) in criticizing the promotion of cultural sensitivity, he equally acknowledges that its promotion is an important and strategic starting point towards cross-cultural dialogue and subsequent cultural diversity and relativity. Thus, the two concepts are complementary than mutually exclusive. The basis of the criticism against cultural sensitivity was that, it unwittingly leads to the neglect of the need for social workers to gain insight into their own cultures and appreciate the extent to which their culture offers a single lens through which to view the world (Brydon, 2011:163; Askeland & Payne, 2006:741). Hence, the researcher maintained that cultural sensitivity should be viewed as one amongst several other means towards an end rather than an end on its own. It becomes a gateway towards inter-cultural and cross-cultural dialogue which as argued by Gray and Allegritti (2002:333) is a pre-requisite for the creation of a cross-cultural world. Cultural diversity and relativity will spontaneously emerge once a conducive environment has been created through cultural sensitivity.

However, the researcher noted that there are other equally critical imperatives towards achieving a cross-cultural world such as the need to address hegemonic structural and institutionalized discriminations of any form and type. Earlier on, Gray and Fook (2004:634) highlighted that there are areas of shared understanding and commonalities in social work that can be universalised and later on, Gray (2005: 235)

suggested that some of the traditional theories and perspectives such as the eco-systems perspective may be used in the domain of international social work. For instance, Gray and Fook (2004:634) emphasize that shared human rights and social justice goals provide a uniting ground for social workers across the world. They further proposed a grounded approach to international social work as well as an expansive approach to professional definition. They conceptualised the grounded approach as implying that we celebrate and recognise commonalities while valuing and including differences.

### **3.3 African social work and the need for indigenisation/Afrocentricity**

Like western social work that developed as a response to contextual challenges as stated by Brydon (2011:150), the development of social work in South Africa has been shaped by various factors and forces over time including colonisation and apartheid (Smith, 2014:325). In the global north and west the pressing challenges of poverty, crime and family disintegration emanating from industrialization and modernisation necessitated the social work response (Brydon, 2011:159), while in South Africa, colonial invasion of an agrarian society was followed by the poor white problem in 1657 which necessitated a need for some form of response (Smith, 2014:325). Smith further discussed how the Dutch Reformed Church and The Dutch East India Company distributed poor relief to farmers following crop failure which was later followed by institutional welfare resources for children and persons with disabilities.

The subsequent discovery of minerals in 1860 led to industrialisation and the migrant labour system (Smith, 2014:326). Similar to challenges that emerged in the west following industrialisation, South Africa also witnessed poverty (black and white), crime, and family disintegration. As a result, in 1948 the Apartheid government led by the Nationalist Party responded with a formal social welfare system which favoured whites at the expense of black people leading to the adoption of a policy of separate development (Smith, 2014:326). The new democratic government inaugurated in 1994 introduced transformation and change calling on all sectors to revisit policies and approaches. This call resulted in the adoption of a developmental policy for social welfare through the White Paper for Social Welfare embracing a developmental social welfare paradigm (Department of Welfare and Population Development, 1997:10).

However, the researcher notes that the developmental paradigm propagated by the White Paper for Social Welfare though a huge improvement from the previous system of separate development; it was not foregrounded on indigenous knowledge systems, culture and traditional intellectual traditions and practices of Africans. As a result, it followed a welfare policy trajectory that remained alien and incongruent with indigenous cultures and traditions. The researcher is of the view that a need exists for indigenisation of social work and welfare policy in South Africa and Africa generally.

Indigenisation is a general term linked to attempts to achieve relevance and appropriateness. This term is applied differently in different indigenous contexts. In Africa, Afrocentricity or Afrocentrism represent an African voice for both indigenisation and indigenous social work. Afrocentricity has over the years developed to become a framework to articulate an alternative voice for understanding African culture and eventually emerged as a theoretical perspective for social work (Pellebon, 2007:176; Graham, 1999:260; Schiele, 1997:803).

Thus, indigenous African social work would be termed Afrocentric social work. Afrocentric social work can be defined as a method of social work practice based on traditional African philosophical assumptions that are used to explain and to solve human and societal problems (Schiele, 1997:803). There are three basic assumptions underpinning Afrocentric social work according to Schiele: individual identity is conceived as a collective identity; the spiritual aspect of humans is just as legitimate and important as the material aspect; and that the affective approach to knowledge is epistemologically as valid as the objective empirical approach.

The above assumptions will be briefly discussed. The first assumption: individual identity as collective identity implies that the whole is bigger than the sum of its parts; one cannot affect one part without affecting the others (Schiele, 1997:803). This assumption resonates with the ecosystems theory in social work. However, the western oriented social work does not fully utilise the ecosystems perspective on the basis of its tendency to hold individuals responsible for their circumstances (individualisation) without due regard for the structural and institutional basis of oppression and deprivations. The focus on a collective identity is supported by a traditional African belief in '*ubuntu*' which presupposes that there is no perceptual separation between an individual and others (Mangaliso, 2001:27). This is so because people are seen as being spiritually connected. Spirituality, from an Afrocentric

viewpoint, can be broadly defined as that invisible universal substance that connects all human beings to each other and to the creator (i.e. God) (Schiele, 1997:803). Although the White Paper on Social Welfare (Department of Welfare and Population Development, 1997) identified *'ubuntu'* (to the exclusion of all other fundamental African values and principles) as one of its founding principles, it did not offer practical guidelines on how this was to be actualised.

As Thabede (2008:234) argues “the adoption of the value base of social work in its pure form from the European and American societal value system breeds role confusion” for social workers in the African context. For instance, Thabede (2008:20) highlights the fact that the belief of social workers in the worth of the individual, the right of the individual to determine his/her own destiny, and the recognition of the individual's potential to govern self, militates against the emphasis of the African worldview on collective good and *ubuntu*. Thabede (2008:235) postulates that individual concerns are subordinate to group interest in the African cultural context.

It is important to underscore that, although the African worldview puts emphasis on collective consciousness, this does not negate the existence and indeed, the significance of individuals making up the collective, but rather that individual identity is construed as a collective identity. Meaning that, individual uniqueness is acknowledged and celebrated as an element of or part of a collective system.

The second assumption about the spiritual aspect of humans being just as legitimate and important as the material component affirms the soul and spirituality as legitimate sources of study and areas to be targeted for development (Schiele, 1997:803). In fact, spiritual development is a major objective of Afrocentric social work. Spiritual development leads to the belief in and understanding of the interconnectedness of all human beings and elements in the universe and, therefore, reinforces the first assumption of collective identity. From an Afrocentric point of view, if there were more emphasis on spiritual development and growth there would be less social problems and human misery (Schiele, 1997:803).

Although there is no formal vernacular word for clan, the work clan appears to resonate closely with numerous ethnic terms for a similar typology of social organisation such as *'lelapa, lapa, ndyangu, umdeni'* as used in the African context. The researcher observed that the clan name system is, but one example of a distinct African cultural

experience or practice signifying a form of group cohesiveness and spirituality that is absent in the western worldview, except in few isolated cases such as the clans in Scotland and Ireland. According to Durie (2012:15) the word clan comes from a Scottish Gaelic word *clanna*, meaning 'children' or 'progeny' or 'family offspring' implying that it is about a kinship group amongst the Scottish and Irish people. The original Scottish and Irish clans were basically extended family groups related by blood and descended from a common ancestor (Milne, 2010:36). However, Durie (2012:15) stresses that the meaning of the word clan has evolved and since changed in Scotland and no longer refer to the same meaning (kinship) as it originally did in Ireland. He argues that in Scotland clans have become territorial, accepting the authority of the dominant local grouping and consequently adopting the Chief as the patriarch, head, principal landowner, defender, military commander and dispenser of justice. As a result, the dependent families or clans or individuals would often adopt the clan name of the Chief as an indicator of affiliation and loyalty to the Chief even when there is no genetic descent from a common ancestor or from the chiefly house (Durie, 2012:16; Milne, 2010:36). It has also been observed by the researcher that in South Africa the Afrikaner nation whose origin can be traced in Europe (Holland) also have a clan name system closely related to the system used by Africans. The Afrikaners have a community practice of naming their children after their ancestors (Kienetz, 1977:559). Kienetz (1977:560) argues that, similar to black Africans, the clan cohesion amongst the Afrikaners signifies a sense of group cohesiveness and spirituality. However, the researcher maintains that the clan system is more pronounced within African communities and as acknowledged by Kienetz (1977:562) the Afrikaner clan system stemmed from and was activated by mixed-race decedents of indigenous Khoikhoi, Europeans and slaves from Madagascar, India and Indonesia.

The sense of group cohesiveness amongst Africans is demonstrated by amongst other things the fact that, whenever there is festivity, a ceremony, or a crisis in most African families, families belonging to the same clan pool their resources together both in cash and in kind (Tshabalala, 1991:73). Consequently, Tshabalala (1991:74) laments that "the African paradigm is underpinned by a value system distinct from the western one". The basic values from which the African paradigm is premised includes amongst others the following: importance of the family, importance of the group, respect for life and elders, fear of God, and a deep commitment to sustaining meaningful community

life through shared produce, shared problems and sorrows as enshrined in the principle of *ubuntu/botho/xintu* (Tshabalala, 1991:74).

Ubuntu refers to humaneness, "a pervasive spirit of caring and community, harmony and hospitality, respect and responsiveness, that individuals and groups display for one another" (Mangaliso, 2001:24). From the above illustrations of the concept of *ubuntu*, it appears that group consciousness and cohesiveness are central characteristics of the African society. Linked to what is commonly known as *Ubuntu* in South Africa is the notion of '*Ntu*' construed as the spirit of God (Schiele, 1997:803). The spiritual alienation that Schiele talks about prevents people from being in line with '*Ntu*'. A new concept known as '*Ntuology*' has been coined and received considerable attention in the Afrocentric literature allowing Afrocentric scholars to drink deep from the well of wisdom found in '*Ntu*'. In the Southern tip of Africa, *Ubuntu* is inextricably linked to '*Ntu*' and the general belief is that all Africans are descendants of a great forefather and ancestor known as '*Ntu*' hence the use of the word '*bantu*' to refer to natives (Schiele, 1997:803).

The third assumption validates an affective epistemology (Schiele, 1997:804). This assumption implies a shift from technical rationality prevalent in western philosophies to mutuality and shared consciousness prevalent in the African paradigm (Schiele, 1997:804). As put by Schiele (1997:804), not only are rationalism and quantification legitimate ways of knowing but also of feeling and intuition. He argues that much of the human experience is non-rational. Effectively, this means that Afrocentric social work acknowledges the linear, materialist understanding of reality, but it draws heavily on an affective and holistic means of knowing and understanding the world. Meaning that feelings (affect) are regarded as a means to offset the excessive emphasis on rationality found in the Eurocentric perspective (Schiele, 1997:803).

On the basis of the above assumptions, Afrocentric social work deduces that the main cause of social problems is oppression and spiritual alienation. The Eurocentric value system undergirded by materialism, objectification, individualism and inordinate competition can become a fertile breeding ground for oppression and spiritual alienation (Schiele, 1997:803). Thus, the methods used within the framework of Afrocentric social work intervention, according to Schiele (1997:803), focuses on the following domains:

- Transforming people from suboptimal to optimal thinking
- Fighting against political, economic, and cultural oppression, cognizant of the fact that cultural oppression is the foundation of all others.
- Building on community strengths particularly their skills and talents.
- An affective helping relationship that discourages aloofness and objectivity.
- Mutuality within the helping process implying that both the helper and the helped are affected and can learn from each other.

In summary, the above section dealt with the Afrocentric paradigm and its implications for Afrocentric social work. It is clear from the discussion that in our quest to create relevance in social work practice, education and research in Africa, Afrocentric social work stands as a desirable option. It is therefore critical that Afrocentric social work be developed optimally to allow for the possibility of it making a meaningful contribution to the international social work domain, without which it will be impossible for Africa to make its contribution. Thus, the following section addresses the intersection between Afrocentric social work as an indigenous form of social work in Africa and the international social work domain.

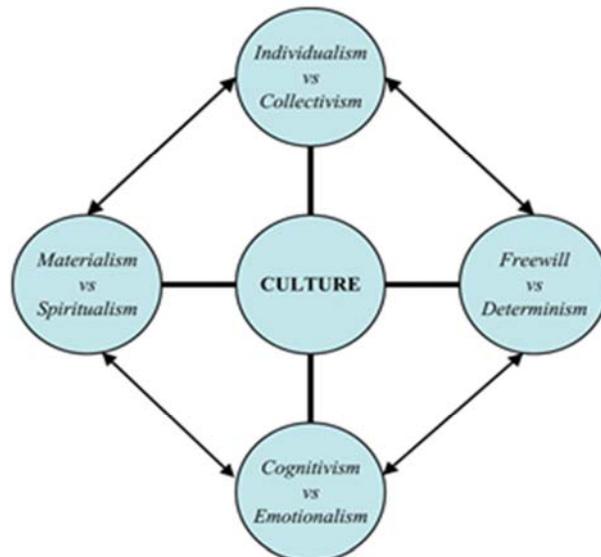
### **3.4 The intersection between indigenous and international social work**

To this end, the domain of international social work has been dominated by 'globalised western traditions' conceived as universally applicable (Askeland & Payne, 2006:735; Haug, 2005:128; Gray & Fook, 2004:630). While Sewpaul (2005:213) has questioned the universal applicability of social work values as propagated by western social work and the domain of international social work. Furthermore, Haug (2005:128) argues that the discourse on international social work is not globally inclusive as it is dependent on one's ability to speak with the conceptual and linguistic capacity of the west who constructed the discourse. More recently, Brydon (2011:163) added to the list of concerns regarding international social work, highlighting amongst others, the fact that western social work in its current form and standard is available only to a minority of people of the world and has no capacity to achieve mutual exchange and dialogue at a global level due to the existence of unequal power relations reflected by the positioning and exclusive hegemony of the western paradigm in relation to others. The above assertion by Brydon affirms an earlier observation by Marais and Marias (2007:812)

that indigenous beliefs were never incorporated into social work's core values and concluded that it was therefore not possible to identify a unified worldview of social work. Meaning that as things stand currently, existing paradigms are not afforded equal value and respect in shaping social work education, practice and research. Consequently, there is no opportunity for different cultural contexts to learn from each other. This status quo remains despite the fact that culture permeates all spheres of life and the acknowledgement that 'no culture is absolute' (Brydon, 2011:163). As articulated by Marais and Marias (2007:813) and Laungani (2004:35), there is a need for social workers to seek a deeper analysis of the implications of culture for humans and how they view the world.

Thus, Brydon's (2011:160) framework for cultural relativity provides a vital tool towards realising the dream of achieving a contrapuntal epistemology to undergird international social work. Using the above author's framework, we can now populate various fundamental cultural themes and precepts that could be universalised based on inputs from different worldviews as outlined in figure 1.

**Figure 1. A framework for cultural relativity.**



Kerry Brydon International Social Work 2011;55:155-167

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Figure 1. The framework for cultural relativity (Brydon, 2011:164)

The framework for cultural relativity enables social workers to appreciate different worldviews and apply them accordingly when working with clients. For example, when working with clients from a Eurocentric worldview, the social worker's approach to issues would centre on individualism, freewill, cognitivism and materialism. When dealing with clients from the African worldview, they may lean towards collectivism, determinism, emotionalism and spiritualism. The framework for cultural relativity allows the social worker to work with all these worldviews without a hierarchy and dominance of one worldview by another, leading to appreciation of cultural relativity.

According to Brydon (2011:164), there is an urgent need in social work to develop a body of theory, skills and values that afford all cultural paradigms equal status and respect. One way to construct this, she argues, could be to position our understanding of social work as involving a kind of information flow between social work and a number of different cultural paradigms. The above is achievable given that the existing cultural paradigms in their diversity have the capacity to interrelate both to each other and to social work, suggesting that the interplay of forces is more important than differences between the paradigms (Brydon, 2011:164).

The international social work discourse has become so vital in contemporary social work that it is in the best interest of social work scholars across the world to engage it. Ignoring it will be at their own peril. As globalisation brings everyone closer and international collaborations become a necessity, the need for a body of knowledge that cuts across and transcends national boundaries becomes even more urgent. However, as pointed out earlier on, little effort has been made to integrate the silenced indigenous voices and knowledges from the post-colonial contexts to the international social work discourse (Marais & Marias, 2007:812). Earlier studies show that, where efforts were made to make service delivery and social work education culturally relevant, it has been done in a context of the dominant Anglo-American theories and practices (Coates, 2003:11; Healy, 2001:6). More recently, Brydon (2011:160) acknowledged the difficulty associated with accepting and incorporating other worldviews into one framework, but warned that contemporary discourses on cultural competence and sensitivity do not provide a sustainable solution to this challenge. She challenged social work scholars to move beyond the proverbial notions of cultural sensitivity and competence and embrace cultural relativity. The researcher concurs

with Brydon (2011) and maintains that knowing (competence) and being sensitive to own and the diverse cultures of others will not lead to the redressing of the historical domination of Eurocentric paradigms in mainstream and international social work, but would instead perpetuate the hegemony of the dominant Euro-American cultures.

It is disconcerting that indigenisation as a process as well as the need for the development of indigenous social work theories and methods have not occupied centre stage in the international social work discourse. Indigenisation is hardly a global concern, "...[e]xcept for some non-western scholars working in the west, American and European scholars are not concerned with indigenization as does the African and Asian scholars when applying western paradigms to their own societies" (Kjellgren, 2003:160). However, 'indigenization' and 'internationalization' are complementary rather than mutually exclusive. It would be almost impossible to realize the true objective of international social work when a significant part/element of the world social work fraternity is left out of the discourse. Therefore, international social work through its various governing bodies should take on the mantle of promoting indigenization and indigenous social work.

Due to the devastating effect of colonisation and imperialism, it is vital that post-colonial contexts first deal with the effects of colonisation. On the one hand, decolonisation refers to "a process by which people peel away the psychological and spiritual effects of colonisation through a facilitated journey of learning the truths of their history" (Bell, 2006:14). On the other hand, Murphy (2003:2) sees decolonisation as "the stripping away of the unwanted layers of other people's culture, accumulated over generations, to expose and rediscover the vivid colours of one's cultural heritage".

The researcher contends that without decolonisation, the indigenisation process is likely to be compromised and lead to the re-invention of the wheel. Therefore, decolonisation should ideally precede indigenisation. Thus in Africa, similar to other post-colonial contexts such as Asia, the search for relevance in social work has to start with decolonisation. This is so because, the rampant effects of colonialism are now cloaked in respectable garb and continue to wreak havoc through generations and generations of its victims (Jackson, 2004:86). Most importantly, the decolonisation project becomes urgent because of the guileful manner in which post-colonisation happens.

The researcher argues that, as in other post-colonial contexts like Asia, Africa too has to undertake a journey of decolonisation coupled with engagements with critical conscientisation and different forms of emancipatory practice to address the harsh realities of colonial destruction. As Smith (2008:373) argues, “the history of social work in South Africa [and by implication and extension Africa] cannot be separated from that of colonisation and Apartheid”. Similar sentiments were shared by Mupedziswa (2001:293) earlier on when he argued that social work in post-colonial contexts such as Africa remained entangled in a struggle for relevance because its content and outlook remained imbedded in first world principles and approaches. In view of the above situation in Africa, some scholars have challenged the profession of social work to return to its original domain of structural change and social justice (Smith, 2008:374; Sewpaul & Holscher, 2004:39).

The debate on the need to refocus on structural change and social justice is taken further by Smith (2008:374) who argues that “...a unique set of internalised and structural oppression of class, race and gender characterising post-colonial contexts calls for ‘critical conscientization’; engagement with oppression and issues of power; a commitment to radical transformation; changes in epistemologies and efforts to change material conditions”. Smith further proposes that radical and critical forms of social work practice based on a combination of a structural, modernist analysis as well as post-modernist critical theory must form the basis of social work training.

However, the researcher takes exception to Smith’s (2008:374) insinuation that a modernist and post-modernist critical theory should form the basis upon which radical and critical social work should be developed. The reason for such dissension is that modernity and post-modernity respectively, are part of the problem as they are entangled with coloniality. Therefore, we cannot use theoretical and conceptual constructs associated with coloniality to solve African problems emanating from coloniality. We need new decolonial conceptions that transcend modernity and post-modernity and hold potential and possibilities for new ways of being, thinking and knowledge creation as an alternative to coloniality-derived options. Building on the foundations cemented by African scholars (Osei-Hwedie, 2011:138; Midgley, 2008:31; Osei-Hwedie & Rankopo, 2008:138; Smith, 2008:374; Thabede, 2008:239; Sewpaul & Holscher, 2004:39; Mupedziswa, 2001:293), the researcher accordingly advances that

a truly indigenous African social work epistemology can only emerge following a decolonisation process which will include, amongst other , critical conscientisation.

The researcher holds that for African scholarship to fully appreciate the value of decolonisation, it is imperative that an understanding of colonisation is first sought. As eloquently captured by several decolonial scholars, the meaning and impact of colonisation goes beyond the physical act of building colonies and dispossession/invasion; it incorporates an internalised process of valorisation of the coloniser's culture and the denigration of the colonised culture (Hart, 2002:85; Laenui, 2007:357; Matsuaka, 2007:35). Furthermore, internalised colonisation occurs when negative racial attributes and expectations (common tactics of colonisation as discussed above), form a person's belief about themselves and can result in negative self-image, and self-harming behavior (Laenui, 2007:357). The researcher re-asserts Laenui's (2007:357) definition of colonization, which talks about both the physical act of colonization as well as internalized colonization which occur when negative racial attributes and expectations form part of a persons' belief about themselves and resulting in negative self-image and self-harming behavior. Thus, coloniality in essence denotes the long standing power patterns that originate from colonization and that are now exercised in the absence of the colonial administration (Maldonado-Torres, 2007:243). Maldonado-Torres (2007:243) distinguishes between three forms of coloniality, that is coloniality of power, coloniality of knowledge and coloniality of being. Simply put, coloniality refers to the imperial/colonial organization of societies. Tlostanova and Mignolo (2009:132) further illuminate the coloniality concept, unearthing important aspects of this concept that have been hidden. They argue that at a conceptual level, coloniality is the hidden side of modernity; it is like the unconscious, the hidden weapon of both the civilizing and developmental mission of modernity (Tlostanova & Mignolo, 2009:132). Therefore, as argued by Maldonado-Torres (2007:243) it is vital to underscore the fact that the long standing power patterns originating from colonisation continue to be exercised even after colonialism has ended. This is to be found in the on-going struggles between the indigenous cultures and the so called hegemonic cultures brought forth by Eurocentrism (Brydon, 2011:157). According to Brydon (2011:157), culture denotes society's ways of responding to social needs and problems on the one hand. On the other hand, the words knowledge and culture can be readily interchanged and taken to mean the same (Huggins, Macklin, & Glendinning, 2008:22). Thus, culture refers to both the societal

response to social needs and problems as outlined by Brydon (2011:157) and as a knowledge system as defined by Huggins et al. (2008:22). Hence, one of the key tools used by colonialists against their colonized victims was the destruction of indigenous cultures and their replacement with hegemonic Eurocentric cultures. It is against this backdrop that the researcher argues that post-colonial contexts need to undergo a process of decolonization in order to address the challenges of coloniality.

Decolonisation is a critical analysis of western informed ideological frameworks, and while it is able to link to, and find commonalities with, the left and/or right political ideologies, the primary focus remains on deconstructing and challenging the ideology of colonisation (Hart, 2007:84; Laenui, 2007:357). Decolonisation calls for “*grounding our theories, anchoring them, on the reflections non-academics make about social life as they live it, and elaborating theory with them instead of about them. The struggle for decolonizing knowledge needs to go beyond developing research projects from and with the historically marginalized to actually elaborate theory based on the reflections people make about social life...*” (Reyes-Cruz, 2008:656). Decoloniality refers to the decolonization of knowledge and being by epistemically and affectively de-linking from the imperial/colonial organization of society (Tlostanova & Mignolo, 2009:132). Thus, on the strength of the above arguments, the researcher maintains that decolonisation as a process should precede indigenisation in social work. Once the profession and academic discipline of social work in Africa has been decolonised, a truly African indigenous social work epistemology with potential for a meaningful contribution to the international social work body of knowledge will emerge. African social work scholarship would be able to create its own relevance instead of finding relevance in the current Eurocentric and hegemonic knowledge base of social work. The researcher recognises that, the significant difference between seeking and creating relevance is that the latter is one of agency and instrumentality by using the instruments around one to develop a sympathetic portfolio of circumstances to suit one’s desires. The former is merely a hope-laden and opportunistic quest that might not necessarily yield the desired ‘set’ of outcomes. Therefore, decolonization becomes a means towards creating own relevance, without which the social work profession is likely to be compelled by default to seek relevance.

Following the discussion of the concepts of colonization vis-a-vis coloniality and decolonization vis-a-vis decoloniality, the researcher now moves to discuss the

process of colonization, decolonization and indigenisation as conceptualized by various scholars. The five stages of colonisation, and decolonisation are conceptualized and explained by an Australian scholar by the name of Laenui (2007:357). The five stages of colonization and decolonization are a useful and succinct way of understanding the past and providing inspiration for a path for the future (Laenui, 2007:357), while the process of indigenization as conceptualized by Asian scholars Cheung and Liu (2004:58) and Yip (2005:596) is presented at the end.

➤ The process of colonization

Stage 1. Denial and Withdrawal:

According to Laenui (2007:358) at this first stage, colonisers deny indigenous peoples' culture and moral values. An example of Australia's case is given where indigenous peoples' humanity was denied and withdrawn in the process of colonisation. The researcher observed that a similar experience was witnessed by South Africans when colonial settlers arrived in Africa. The African people were reduced to inferior sub-humans. According to Sithole (2016a:25), given the lived experiences of black subjects under the bane of colonisers, the existential condition of black people should be engaged from the '*ontological zero point*' which means that they should be understood from their lived experiences and their form of living that is reduced to non-existent (lack of ontological density). This in the researcher's view speaks to the first stage of denial and withdrawal in the colonisation process.

Stage 2. Destruction/Eradication:

At this stage, the destruction of culture, social systems is witnessed by the colonized in the hands of the colonisers. The case of Australia described by Laenui (2007:358) shows how this stage ushered mass murders, massacres, eugenic breeding programs aimed at assimilation/absorption and forced removal. Similarly, in South Africa black people witnessed a prolonged period of mass genocides and dispossession of African natives of their land and livestock. As argued by Sithole (2016b:182), black people in Africa are amongst the inhabitants of the world whose cultural and spiritual power has been destroyed (epistemicides). In his lamentation of colonialism, Biko (1978/2004:31) quotes Fanon's reflections on colonial destruction and eradication of black history on the occasion of intimating that:

*...in an effort to destroy completely the structures that had been built up in the African society and to impose their imperialism with an unnerving totality, the colonialists were not satisfied merely with holding people in their grip and emptying the Native's brain of all form and content, they turned to the past of the oppressed people and distorted, disfigured and destroyed it. No longer was reference made to African culture, it became barbarism. Africa was the 'dark continent'. Religious practices and customs were referred to as superstition. The history of African society was reduced to tribal battles and internecine wars.*

### Stage 3. Denigration/Belittlement/Insult:

Indigenous culture, languages, practices, knowledge and beliefs are denigrated and rendered invisible and valueless and, in some instances, outlawed. These are replaced by the coloniser's model. In the African context, Sithole (2016b:182) argued that black people in Africa represented those whose life was dehumanised, inferiorised and racialized. Similarly, Asante (2006:647) observes that African people were denigrated to holding up the margins of the American and European's world. As a result, he used Afrocentricity as a theoretical perspective and philosophy in order to convey the profound need for African people to be re-located historically, economically, socially, politically, and philosophically from holding up the margins of the American and European's world. This re-location, according to Asante (2006:647), would ensure that Africans freed their minds and shifted from being decentered to being centered on African cultural heritage. It is interesting that Biko (1978/2004:22) describes the denigration process as the bastardisation of Africans and their cultural heritage by colonisers reducing a long history of African life into barbarism. With this in mind, Biko (1978/2004:22) laments that black Africans suffer from inferiority complex as a result of 300 years of deliberate oppression, denigration and derision which make them useless as co-architects of a normal society. It is on the basis of the above assertion that Biko alluded to the necessity as a prelude to anything else that may come of a very strong grass-roots build-up of what he termed 'black consciousness', so that blacks can learn to assert themselves and stake their rightful claim. All of the above assertions attest to the fact that Africans too were denigrated/belittled/insulted as part of the colonization process.

### Stage 4. Surface Accommodation/Tokenism:

In this stage, the remains of the surviving culture are given token regard. According to Laenui (2007:359), this stage creates the 'noble savage' concept and others' definition of what constitutes a 'real' indigenous person. Consequently, Biko (1978/2014:21) expresses his strong distaste for surface accommodation or tokenism as described by Laenui by proclaiming:

*The integration they talk about is first of all artificial in that it is a response to conscious manoeuvre rather than to the dictates of the inner soul. In other words the people forming the integrated complex have been extracted from various segregated societies with their inbuilt complexes of superiority and inferiority and these continue to manifest themselves even in the 'non-racial' set-up of the integrated complex.*

Stage 5. Transformation/Exploitation:

Remnant culture is transformed and exploited by the dominating colonial society. Indigenous art is one example of this stage. In his reflection about colonization, Biko (1978/2004:30) recounts how the coloniser disfigured African cultural practices including traditional spirituality and indigenous knowledge systems and replaced them with western ways that turned African people against themselves. He summed up the logic behind white domination of blacks as about 'preparing a black man for a subservient role in his country'. Having pointed this out, Biko (1978/2004:30) qualifies the transformation and exploitation that Laenui described in stage 5 by describing what a black man has become as a result of colonisation as follows: "... a shell, a shadow of man, completely defeated, drowning in his own misery, a slave, an ox bearing the yoke of oppression with sheepish timidity".

➤ The process of decolonization

Following the discussion of the five stages of colonisation, the following section draws on the subsequent five stages of decolonisation proposed by Laenui (2007:359). These stages are not sequential, like the process of colonisation, people can move between them and stages can overlap. All five stages are integral and interlocked (Laenui, 2007:359) and they are as follows:

## Stage 1. Rediscovery and Recovery

This foundation phase is where people rediscover their history, recover traditional practices and languages and reconnect with country and kin (Laenui, 2007:360). It is a time of renewed sense of identity, of recovering knowledges. It is significant that Laenui (2007:360) notes that people may arrive at this stage by curiosity, accident, desperation, escape, coincidence, fate, or - spirituality. In the South African context, Biko (1978/2004:34) called this stage 'the re-awakening of the sleeping masses'. He argues that the only vehicle for change before starting on any programme with people who have lost their personality is to make the black man come to himself; pump back life into his empty shell; to infuse him with pride and dignity, to remind him of his complicity in the crime of allowing himself to be misused. He termed this an 'inward-looking process in black consciousness (Biko, 1978/2004:31). Most importantly, Biko (1978/2004:34) emphasised that "it shall have to be the black people themselves who shall take care of this programme...as a living part of Africa and of her thought". To bring this closer to home, this first stage in South Africa would centre on the restoration of the African cultural heritage. This may cover the three aspects of decoloniality of being, power and knowledge as propounded by Maldonado-Torres (2007:243). Decoloniality of being would relate to the restoration of the true identity of people while decoloniality talks to the reclamation of the power to choose and act in the best interest of self without coercion and undue influence from somewhere else and finally, decoloniality of knowledge relates to the restoration of indigenous knowledge systems. All these dimensions of African ontological experience were destroyed and eradicated by coloniality.

## Stage 2. Mourning

The mourning phase is a time where the feelings of anger and injustice need time for expression in order for the healing to begin (Laenui, 2007:364). Laenui cautions that some people can become lost in this phase, unable to move towards healing (2007:364). Therefore, as the researcher observed in the case of South Africa, some people may be harboring anger and unresolved issues arising out of colonization. As indicated, even after many years post colony, colonization continues to cause havoc

amongst its victims. Some people might have completely lost their true identity and may even deny that such loss happened. The researcher is of the view that patience is required for people to be able to move forward. Such patience also means accepting that it will take time for people to achieve what Biko called 'returning to self' and 'reawakening of the sleeping masses'.

### Stage 3. Dreaming

This is a phase of strengthening and revaluing people's philosophy and knowledge. Laenui (2007:365) sees this phase as the most crucial for recovery, describing it as a phase for '*building the Master Recovery Plan*'. The researcher similarly views this as vital because it is instructive of people to envision a new way of being, knowing and power in a more practical sense through setting goals and planning how to achieve such goals. It is a call for action in all sectors of the society including academy and disciplines through their education, research and practice roles. For instance, this is a stage where social work as a profession begins to plan and re-deploy a new decolonized form and content of social work. By extension, as per the imperative of this study, the decolonized form and content of social work will cascade to carving out guidelines about ways of coping with DS that are not add odds with African ways of being, knowledge and identity at the familial level.

### Stage 4. Commitment

From the dreaming phase comes the opportunity for commitment to a direction in which society must move (Laenui, 2007:365). Thus, once a plan on decolonization has been agreed upon and actioned, there will be a need to reinforce it with an unwavering commitment in order to sustain the process. This may take many forms including continuous engagement between stakeholders and role players in social work through the use of various communication mediums including publications, conferences, collective agendas, pledges and mottos.

### Stage 5. Action

The action in this phase is pro-active, not reactive. This phase is not the responsive action to challenge injustices or action to ensure survival; it is not punitive action, it is positive action (Laenui, 2007:365). The decolonization process should not be aloof and

abstract, but rather talk to day to day issues that will have to be contended with on an on-going basis. Therefore, action will always be key to the process. As plans are adopted and actioned, new issues and challenges will emerge and call for action. Therefore, the process may need to be multi-faceted and multi-dimensional so that issues are tackled at different levels. Some action will need to be proactive while other situations may call for reactions and all these may occur at grass-roots level or coordinated at institutional, structural and systemic levels.

➤ The process of indigenization

In the social work fraternity, one proponent of indigenous social work in Africa, Osei-Hwedie (2002:312), defined indigenous social work as locally developed social work characterised by appropriateness of theories, research and practice to the cultural values, norms and philosophies of a particular context. In line with the above definition, it can be deduced that indigenous social work refers to social work developed locally using local knowledge, perspectives and philosophies. Having defined indigenous social work thus, the following discussion will explore indigenisation as a process. While Midgley (2008:31) defined indigenisation in social work as a process of making theories and models of social work to be appropriate to the context, he further defines 'appropriateness' as implying that professional social work roles must be appropriate to the needs of different countries and social work practice and that additionally, practice must also follow societal procedures, norms, ideas and practices. From the above definitions, indigenous social work stands out as a concept describing a form and content of social work developed locally and indigenization as a process within social work describing a process through which indigenous social workers attempts to create relevance by adapting a form and content of social work imported from a different context (particularly western social work) to Africa. It is important to distinguish between indigenous social work and indigenisation as a process in social work. The indigenisation process on the one hand, naturally follows once there is a realisation that foreign social work has been transmitted on a different context and consequently irrelevant and ineffective in responding to local social challenges. On the other hand, indigenous social work refers to culturally relevant and specific social work knowledge

and practices, which may or may not be universal or even cross-indigenous (Gray & Coates, 2010:615).

The researcher takes his cues from what is argued by Brydon (2011:160) that any form or content of social work is indigenous to a particular socio-cultural and political context. The question is which context is it? In some cases it is correctly indigenous to the context from which it is conceptualised and practiced, but in other cases the kind of social work practiced, taught and researched is imported from a different context and consequently found to be out of fit and irrelevant to the host context. It is in cases such as Africa where foreign social work has been imported to host countries mainly through colonisation that the indigenisation process is required to adapt foreign social work to local contexts. According to Gray et al. (2008:8), the call for indigenization is a result of a growing realization of the limitation and irrelevance of western models of research, education and practice on non-western cultural contexts. They question the universal application of western originated methods and models on diverse cultural contexts. Like Midgley (2008:40) and Osei-Hwedie (2002:312), Gray et al. (2008:7) contend that indigenization in social work refers to attempts to change dominant or mainstream methods and models developed in western contexts, and make them relevant to culturally diverse client populations.

However, the researcher disagrees with Gray et al.'s (2008:8) assertion that indigenisation also refers to a process of developing a form of social work which seeks effective culturally appropriate research, education and practice. This disagreement arises from the observation that indigenization in social work mainly centres on adapting that which is foreign to the local context, but once we begin developing culturally appropriate research, education and practice; we are in the realm of indigenous social work. We cannot indigenize that which originates from the local context but, rather, that which has been brought from a different context. As indicated earlier, all forms of social work are indigenous, whether espoused as such or not, whether American, European or Asian. This is the gist of the difference between the approach proposed by Gray and Fook (2004:632), on the one hand, and the researcher, on the other.

There are various conceptualizations of the process of indigenization of social work by different theorists. Amongst such conceptualizations, the indigenization process has been conceptualized by Yip (2005:596) and Cheung and Liu (2004:58) from the Asian

context in a more or less similar manner as comprising five (5) major phases. These authors unanimously theorized that, social work enters new territory through a transmission stage but is followed by indigenization as there is reaction to various aspects of the model transmitted, followed by authentication as there is reorganization to suit local circumstances. They argue that eventually, new models and new understandings emerge, capable of being transmitted back to the original source.

Specifically, Yip (2005:596) suggested five components of indigenization in social work practice, including the adaptation of western social work practice, implementation in the local context, a local indigenized criticism of the impact of professional imperialism and colonialism, and a re-engineering of skills and techniques.

Following a corresponding logic, for practical intents and purposes, Cheung and Liu (2004:58) developed a set of five (5) guidelines that can be followed as part of the indigenization of social work process in post-colonial developing countries on the basis of their theorization about the transmission, reorganization and authentication of western social work. Their guidelines are discussed as follows:

#### Stage 1. Building an indigenous foundation:

The first stage entails building an indigenous foundation, such as a philosophical basis, theories, working principles and approaches, in social work education. This is a phase where social workers use indigenous knowledge systems, worldview/s and philosophies as a basis for the development of social work theory to guide practice, education and research. This is crucial given that without a solid indigenous foundation, the whole indigenization process is bound to fail. The researcher has observed that this is a major challenge for South African social work and indeed the entire African social work fraternity. Thus, the scholarship in South Africa and the entire African continent is grappling with this stage at the moment through a series of consultative forums and dissemination of information through academic journals and other forms of engagement with the decolonization discourse.

#### Stage 2. Addressing social problems:

The second stage involves addressing social problems and developing strategies within an indigenous social and developmental context. South Africa is certainly not yet at this stage given that there has not been a development of indigenous or even

indigenized theories and models to address social problems. The researcher's observation is that there is still a heavy dependence on western social work. However, Afrocentric social work theory does exist as developed in the African diaspora. Although African, it has not yet gained traction in Africa in general and South Africa in particular.

#### Stage 3. Redefining focus:

The third is to redefine the central focus, knowledge and value bases of social work practice from western countries and develop indigenous conceptual frameworks and methodologies. As indicated on stage 2, Afrocentric social work has been developed somewhere else in the African diaspora, but it has not filtered down to practice in South Africa. Therefore the central focus, knowledge and value base of social work remain western dominated. It is hoped that through interventions such as this study, the move towards redefining the focus of social work in South Africa will be accelerated.

#### Stage 4. Acknowledging historical, cultural experiences of indigenous people:

The fourth is about acknowledging the historical and cultural experiences and realities of indigenous peoples. This stage can only be realized through an in-depth exploration and description of the lived-experiences of indigenous South African people as done in this study. Therefore, more phenomenological studies are required to form a solid basis from which a proper acknowledgement of the historical, cultural experiences and realities of indigenous South African can be sought—based on empirical evidence. This will have to be updated on an on-going basis to cater for the fluid nature of these experiences and realities.

#### Stage 5. Rolling-out indigenous social work:

The fifth stage is about conducting social work practice from the perspective of extant local community expertise and resources. Similarly, this has not been done in South Africa. However, it forms part of the objectives of this study, in a sense that the indigenized social work guidelines developed through this study will hopefully serve as a springboard for the commencement of Afrocentric social work practice in various localities with African families of children with DS.

The foregoing discussion on the interaction between indigenous and international social work laid bare an undesirable state of unequal relations and continued

hegemony of Euro-North America on the knowledge base of social work at both macro (global) and micro (national and below) levels. Consequently, various forms of indigenous social work as may be found mainly in post-colonial contexts around the world particularly in Asia, Africa, Australia and New Zealand are parochialised to their indigenous context (micro) and find no accommodation and expression at macro level. The domain of international social work remains an exclusive preserve of western epistemologies, partly because of the destruction of indigenous knowledge systems through colonization and largely due to continued coloniality in post-colonial contexts. Thus, to effectively deal with this situation of continued inequalities, social work scholars, particularly those in Africa need to appreciate the nature of the colonization process in order to find the best and most effective methods to follow when it comes to decolonization and indigenization process. There are already some good examples from Australia and Asia. Indeed, the state of international social work calls for a serious confrontation of the status quo and challenges social workers to urgently find ways of opening up the space for alternative epistemologies to emerge particularly from the post-colonial contexts that were previously and continue to be silenced to this present day. This will effectively bring about a shift in the geography of knowledge production.

### **3.5 Summary of the chapter**

This chapter discussed the historical and contemporary overview of social work as well as the need for decolonization and indigenization. The landscape of international social work, African social work, the need for decolonization and indigenization were also discussed including various conceptualisations and guidelines suggested by some scholars regarding the processes of colonization, decolonization and indigenization. The chapter demonstrated that a historical analysis remains the best method of understanding the development of social work given that the profession has been shaped by various social, political and economic forces. Thus, an understanding of the role of such forces enables a more rigorous analysis and the development of more appropriate solutions.

The following chapter will discuss the African family, DS and its associated specialized medical services as well as its implications on the African families' health behaviors. The chapter will also discuss contemporary social work services in health care settings in South Africa.



## **CHAPTER FOUR**

### **ILLUMINATING THE AFRICAN FAMILY, DS AND ITS ASSOCIATED SPECIALISED MEDICAL SERVICES AND IMPLICATIONS, AFRICAN FAMILIES' HEALTH BEHAVIORS AND CONTEMPORARY SOCIAL WORK SERVICES IN HEALTH CARE SETTINGS IN SOUTH AFRICA.**

#### **4.1 Introduction**

This chapter gives a detailed context of the African family as an institution, its structures and functioning. It also provides a historical analysis on how the institution has been shaped and changed over time. There is, in addition, a focus on DS as a medical condition as well as available specialized medical services, including genetic counseling services, followed by a discussion on the implications of having a child with DS. The nature of contemporary social work practice in South Africa forms part of this chapter. The chapter also includes the discussion on the documented health behaviors of Africans and their implications for social work practice in health care settings as recorded in the literature.

#### **4.2 The nature of the African family system**

This section presents a discussion on the African family. Before delving on the discussion, the researcher will clarify the contextual understanding of the terms "family" and "household." It must be noted that the researcher was confronted with a challenge of lack of recent literature examining the notion of the 'African family'. Consequently, whatever available literature used in this discussion is dated. The dominant narrative used within the conventional discourse of the family as a social system presumes a shared understanding which is delusional and leads to conceptual confusion. The confusion emanates from the sharp difference in conceptualization of family between the African and western paradigm. On the one hand, in western society the term 'family' is generally understood to refer to the conjugal pair who maintain a household with their offspring or adopted children while anyone else outside of this circle is referred to as 'extended family' (Siqwana-Ndulo, 1998:408; Russell, 2003b:162). On the other hand, the African society generally views "family" as a much wider circle of

people (Siqwana-Ndulo, 1998:408). She further argues that, similar to western society, marriage is the basis for 'family' in the African context.

From a review of early literature on African families, it appears that early authors and scholars noted the changing nature of the African family and perceived such changes as a progression towards the more advanced and modernized family forms resulting from exposure to western civilization according to Siqwana-Ndulo (1998:410). According to Siqwana-Ndulo (1998:410), the biased and skewed analysis of the African family described above by early scholars could be attributed to a number of factors including, but not limited to, the fact that traditional marriage procedures including the widespread *lobola* or 'bride price' custom were becoming increasingly ignored by some Africans living in urban areas. For instance, the increasing prevalence of a new phenomenon known as 'cohabitation' where unmarried couples move in, live together, conceive and raise children. This is said to be particularly prevalent amongst young people in urban centers. Furthermore, Siqwana-Ndulo (1998:409) noted the use of the fact that Africans who considered marriage tended to prefer western-style marriages. Consequently, it was claimed that as a result of such changes, obligations and responsibilities to each other and to the society which are enshrined in African marriage procedures were disappearing. She further argued that while some may find merit in the functionalist view of the African family by early anthropologists as described above, "the problem is that because of its Eurocentric assumption about the family, what family household forms evolve among Africans are seen only as corruptions of the 'ideal family type' toward which African families are supposedly evolving" (Siqwana-Ndulo, 1998:409).

Indeed, as observed by Siqwana-Ndulo (1998:409) the work of the early anthropologists who conducted comparative analysis of the African family with the conventional western nuclear family had tremendous influence on the way in which the African households are viewed in South Africa today. There has not really been any serious effort to analyze this family form beyond comparing it to the western 'ideal family type', in the fashion of those early anthropologists. Siqwana-Ndulo (1998:409) demonstrated the above position by highlighting an example of Phillips (1953) whose comparison of features of African marriage to that of past European form affirmed an

implied message that African families were in linear progression towards the supposedly superior, most advanced western-style marriage and the nuclear family.

The increasing number of contemporary texts on African family forms reveals a similar bias and skewed approach to analyzing the African family form (Russell, 2003a:6). A closer look at the literature reveals some points of similarity in the assumptions made about African families and those of other Africans in the diaspora, particularly African American families (Siqwana-Ndulo, 1998:410). Similar to the characterization of African families in Africa, the African-American family too has been viewed negatively as having failed to develop the ideal or 'normal' family. According to Billingsley (1968:18) "this family type consists of husband and wife and their own or adopted children living together in their own household with no other members present" – 'the nuclear family'. However, despite such sweeping conclusions, the majority of African-American families did not conform to this ideal and were found instead to accommodate more members in their households (Siqwana-Ndulo, 1998:410). This author further stressed that the African-American "extended family" has been viewed as an indication of pathology, yet these institutions continue to be reported as a fundamental element of Black American society.

On the basis of the above discussion, it is imperative that the study of African family forms, both in Africa and the African diaspora; recognizes the fact that the African family or household organization is part of a social system with a cultural heritage based on a value system quite distinct from the western one. The researcher observed that the limited text on African family in South Africa seems to view African culture as primitive, subjecting it to unfair judgment based on western culture. Furthermore, such an analysis should include an objective account of the influence of African cultural beliefs and social behavior as they are adapted to various historical developments and periods in their history (Siqwana-Ndulo, 1998:410).

According to the literature review conducted by Siqwana-Ndulo (1998:411), Africans are more likely to reside in extended family households than Whites. Furthermore, the writers who view African family as pathological see it as a "cultural deviant" in the context of western society. Conversely, she noted that there was a growing body of scholarship that viewed African families as being guided by cultural values which can

be distinguished from that of middle-class White families. An interesting finding by Russell (2003a:7) on researching the African family reveals that "... some new circumstantial evidence for the correctness of the idea that blacks in both urban and rural areas have a distinctive system of household formation, quite unlike that operating among whites came from the 2002 census." After a comparison of the frequency distribution of households of various sizes for Whites and African in both rural and urban areas, Russell (2003b:153) concluded that if it was correct that Africans were experiencing a trend towards nuclear family households as a consequence of their participation in the commercial industrial capitalist economy, we would expect this to manifest itself in smaller families in the urban areas where the pressure to individuation, competition, consumption and display are greatest. Following this observation, we would expect some convergence of black and white urban family distributions, but the findings pointed to a different direction. This would mean that, despite the pressure and fierce assault imposed by modernization on the African family system in South Africa, it has remained resilient and retained its unique character distinct from the western nuclear family structure.

The similarity in the close relationship pattern between members of the kinship network of urban and rural African households, however, and the difference brought about by the lack of close kinship relations displayed by Whites is what Russell (2003b:154) found to be striking. Little variation was shown in both groups between urban and rural areas, meaning that the relationship patterns amongst white families in rural and urban areas remain the same and the strong kinship relations amongst black African families in urban and rural areas is the same. Race, ethnicity and culture had a significant influence over location and determination of household distribution (Russell, 2003b:154). Significantly, with the benefit of hindsight, Russell (2003b:155) contends that earlier anthropological analysis of the African family failed to interpret their data correctly because of "the imposition of preconceived models imported from western sociology onto the data."

The researcher is of the opinion that the argument by Siqwana-Ndulo (1998:411) is correct: the prevalent conceptualisations of the African family ignore the fact that African social reality is determined by a particular philosophical view of life, which defines the society and the individual's place in it and the world. No less important is

that Siqwana-Ndulo cites Mbiti's (1969:108-109) assertion that African individuals see themselves and their roles in society only in relation to the whole community to which they belong. In traditional life, the individual does not and cannot exist alone except corporately. He owes his existence to other people, including those of past generations and his contemporaries. He is simply part of the whole. The community must therefore make, create or produce the individual; for the individual depends on the corporate group. Only in terms of other people does the individual become conscious of his own being, his own duties, his privileges and responsibilities towards himself and towards other people. Mbiti argues that this is a deeply religious view of life, and it is "a cardinal point in the understanding of the African view of man" (Mbiti, 1969:109 cited by Siqwana-Ndulo, 1998:411).

Therefore on the basis of the critical analysis provided, it is prudent to maintain that the African paradigm provides a reliable basis from which the practices of African family and household arrangements could be understood. This kind of critical analysis and appraisal of the African family and its household arrangements enable us to acknowledge the impact of the lived experiences and conditions in which they find themselves. Most importantly, the researcher acknowledges that through critically analyzing the lived experiences of African families as reflected in the literature, he was able to recognize the influence of their enduring cultural values and traditions on the ways in which they organized themselves and dealt with life challenges.

African marriage and family have always been at the core of a unique and complex social organization underpinned by the value system unique to African societies (Siqwana-Ndulo, 1998:415). The author stresses that in South Africa, the institution of marriage, family, household and the entire social organization from the early days of polygyny have been geared toward the community interest and to ensure that everyone's needs are taken care of. There was a well-defined code of behavior with everyone's place, responsibilities and obligations in the family and society. She maintains that African families and households in contemporary South Africa still strive to fulfill those obligations to one another (Siqwana-Ndulo, 1998:415).

Additionally, literature on traditional African families shows that they follow a patrilineal kinship system (Penn, Watermeyer, MacDonald & Moabelo, 2010:12; Meiser, Irle,

Lobb, & Barlow-Stewart, 2008:439; Mbae, 2005:19). A patrilineal kinship system refers to a kinship system where kinship and descent are traced through the paternal line (Meiser et al., 2008:439). Under the patrilineal system, the lines of descent and authority are traced through fathers, a man and his brothers, their children and their sons are counted as members of the same family due to common descent (Nyathi, 2005:10).

A recent study on naming practices amongst traditional African people by Chauke (2015:304), confirmed that naming practices are very important amongst the traditional African people because names are given to children to mark the testimony of what a society holds dear in a given community. Chauke (2015:304) further argues that names bear testimony to the history and culture of a particular nation or people. According to Chauke (2015:305), the Shangaan (Vatsonga) as a people have a tendency to enshrine any event that is considered memorable in a name and therefore names are chosen for their beneficial influence on the life and character of the bearer.

The researcher concludes that, African households have never been exclusively about the man and his wife or wives and their children. What the westerners call "extended family" among Africans refers to a collectivity of people who either live together in a single household or multiple households, whose relationship could be traced through kinship or marriage and who consider themselves a '*clan*' rather than family as conceived in the western world. The term "extended family" itself, makes the basic assumption that households are made of the core family consisting of a husband, his wife and their children. All the others are viewed as extensions of this core family. This does not resonate well with the African conceptualization of social organization despite the fact that the word family is commonly used and has become part of a dominant narrative that even Africans use despite its illusion and conceptual confusion. The concept of 'family' in a legal sense carries similar confusion. However, the legal system in its search for clarity has sought to adopt a more fluid sense of the concept 'family' that is accommodative of different types and forms, with a fusion of both the western and customary systems. Indeed, African families can be best understood from an Afrocentric prism as described in this section. The following section focuses on the nature of specialized medical services available for the African families raising children with DS in South Africa.

### **4.3 The DS condition and related specialized medical services**

The following section discusses the management, treatment, care and support for children with DS in relation to available specialised genetic services offered by the Department of Health (DoH). Such services include amongst others: medical genetic services, genetic counselling services as well as a range of other related therapeutic services.

#### **4.3.1 Specialised medical services**

According to the South African government's Policy Guidelines for the Management and Prevention of Genetic Disorders, Birth Defects and Disabilities, DS can be managed and prevented at various levels such as primary, secondary and tertiary levels through the use of a multi-disciplinary team involving both medical and allied-medical professionals including social workers in health care settings (DoH, 2005:12).

The primary prevention of DS is aimed at giving information to people, particularly potential mothers, about DS so as to prevent its occurrence (DoH, 2005:12). Social workers can play a significant role in this case through using the community work method. This means that social workers in health-care settings may need to revisit their scope of practice and reallocate resources at their disposal to doing community work in addition to their clinical work. The DSD's (2013) Framework for Social Welfare Services (FSWS) describes this level as prevention, where the delivery of services focuses on strengthening and building the capacity, self-reliance and resilience of service beneficiaries while addressing individual, environmental and societal factors to create conditions that enhance or support wellness (DSD, 2013:29). The DSD further stresses that services at this level are focused on preventing development needs from developing into social challenges or risks. This level of service delivery includes the developmental services dealt with in the White Paper for Social Welfare (RSA, 1997) and the primary prevention of the development of a 'disease' or problem. Social workers may easily adapt their community outreach programmes to the various primary prevention programmes and interventions available in the health care setting. A screening test known as maternal serum triple screen is used by the medical team as a primary prevention measure for DS through the identification of pregnancies at high

risk for certain foetal abnormalities including DS (DoH, 2005:12). Therefore, social workers may collaborate with the multi-disciplinary team and incorporate this screening test to their community work programmes. The role of social workers in this case would be the facilitation of community work programmes which may take different forms depending on the need from the ground. These may involve community education where the intervention will be geared at addressing the lack of information and ignorance through capacitating community members with knowledge, skills and attitudes (KAS). They may also involve social marketing, where available social services are under-utilised because the community members' perceptions of such services is negative either due to stigma or socio-cultural stereotypes and the community practitioner intervenes to change the image of services to one that community members can identify with and eventually improve utilisation (Weyers, 2011:11).

Secondary prevention involves initiatives such as the provision of genetic counselling to all pregnant women of AMA (>35 of age) (DoH, 2005:17). Genetic counseling is a relatively new field in South Africa as stated by Penn, Watermeyer, MacDonald and Moabelo (2010:16). Therefore, it is important that one defines it before proceeding to discuss how the health care settings deal with the prevention and management of DS. Genetic counseling is defined as an educational process by which individuals or relatives, at risk of a congenital disorder, are informed of the nature of the genetic disorder, the probability of developing or transmitting it and the options available to them in which it can "be prevented, avoided or ameliorated" (Harper, 2004:3).

Additionally, secondary prevention of DS includes voluntary pre-natal diagnosis and selective termination of pregnancy for affected fetuses (DoH, 2005:18). The South African constitution guarantees women the right to selectively terminate a foetus at a specified gestational age of their pregnancies for reasons within those identified as permissible (Choice on Termination of Pregnancy Act No. 92 of 1996). Firstly, a pregnancy can be terminated at 12 weeks for any reason on the mother's request. Secondly, a pregnancy can be terminated between 12 and 24 weeks if it is perceived as having a negative medical, psychosocial impact on the mother, and after that it can be terminated if it will result in the birth of a child with serious medical problems and poses a threat to the mother's life (Choice on Termination of Pregnancy Act No. 92 of

1996). The social worker can also play a role in this instance by providing pre- and post-termination of pregnancy counselling to ensure that the mother is able to accept the procedure and live with peace, without guilt feelings for having the pregnancy terminated.

Tertiary prevention of DS involves managing the condition through initiatives such as neuro-developmental therapy (physio and occupational therapy) and the provision of social support to parents (DoH, 2005:18). The researcher argues that dissemination of the right information to the broader community about DS may contribute positively to clearing myths and stereotypes. This is the place where the social worker could be actively involved using the community education model to equip the community with the necessary information on DS, with the ultimate goal of having the children with DS accepted within their communities. The dissemination of information has been proven to have a potential to improve the level of management and care for the child (DS Bulletin, 1998:22). Attempts at integrating children with DS to mainstream education are being tried with some success examples, despite a fierce criticism from those that are cynical about the initiative (DS Bulletin, 1998:22). Medical management initiatives such as cardiac transplant and thyroid hormone supplementation for children with DS have been shown to be essential in prolonging the lives of children with DS (DoH, 2005:18).

While the constitution makes provision for the right to selective termination of pregnancy, the pro-life sections of the population, arguing on religious, cultural and moral grounds, are expressing strong sentiments against such constitutional provisions. As a result, the availability of medical procedures for prenatal detection and termination of affected pregnancy does not stand as an absolute preventative measure for the occurrence and recurrence of congenital conditions like DS. The researcher is of the view that a great deal of secondary and tertiary prevention will always be necessary and the social workers within this field have to make an effort to be actively involved.

Given the fact that the issue of selective termination of pregnancy is a sensitive one with potentially grave psychosocial implications on the parents, the researcher is of the opinion that the intervention of a social worker can be of benefit to the parents. From

the researcher's observation, it seems that the government's undertaking to integrate genetic services into primary health care is still at its infant stage. A huge proportion of the population has no basic knowledge of genetic conditions, or access to genetic clinics. Where services exist in the form of genetic counselling, it is offered in the narrowest sense that does not utilise the holistic approach to social services and is not offered as an integral part of the public primary health system. In the researcher's view, the training of nurses and other allied medical professionals as genetic counsellors serves to further create an unnecessary duplication of psychosocial services already in existence in the hospital setting.

In compliance with the need for a holistic approach to social service delivery, the researcher observed that most of the hospitals in South Africa have put in place all necessary support services to achieve a holistic approach in total patient care, and this includes the integration of health care social workers who are charged with the responsibility of helping patients deal with the psychosocial implications of their medical conditions.

Furthermore, the researcher is of the view that the integration of social work in the multi-disciplinary team poses a challenge to social workers in health care to take on the mantle of acquiring appropriate knowledge in various medical specialties that they work in, such as genetics in primary health care, so as to begin to develop relevant intervention models that can help curb the unbearable psychosocial and financial cost of raising a child with DS. While, the policy guidelines for the management and prevention of genetic disorders and birth defects (DoH, 2005:19) acknowledges that inter-disciplinary integration of services is essential to foster appropriate client appraisal, the department has not fully utilised this approach from its inception. The researcher also noted that the meetings of the ad hoc committee that produced the above document has been mainly dominated by medical practitioners and has wittingly ignored the role of other allied medical disciplines such as social workers, psychologists, physiotherapists and occupational therapists. As a result, the document fails to put forward a strategy that utilises existing structures and resources in the health care setting and instead seeks to create new specialised services, something that appears to be far from realistic given the current pressing health needs and the budgetary constraints.

The researcher argues that the government is already overburdened with pressing needs to respond to the devastating effects of the Acquired Immune Deficiency Syndrome (AIDS) pandemic and would not afford to cater for a separate cadre of specialised genetic counsellors in health care. As a result, genetic counsellors are not currently part of the public health system. Where they are available, they practice privately and various laboratories that provide testing for genetic conditions employ some.

Having dealt with the various prevention strategies for DS, the following section focuses on medical care. Medical care for individuals with DS includes diagnosis, therapeutic intervention and genetic counselling with psychosocial support (Christianson et al., 2006:17; Christianson & Modell, 2004:233). The medical care for individuals with DS therefore involves three interventions: diagnosis, treatment and genetic counseling.

#### 4.3.1.1 Diagnosis

An early postnatal medical genetic diagnosis can be made using clinical and family history, a physical examination and laboratory testing (Christianson et al., 2006:18; Christianson & Modell, 2004:235). The abovementioned authors further assert that, following confirmation of an early postnatal medical genetic diagnosis, a realistic care plan, taking the family, community circumstances and available health care facilities into account, can then be considered. However, the researcher has observed that this is not widely practiced, except in few medical centres where genetic services are in place.

#### 4.3.1.2 Treatment

According to Roizen and Patterson (2003:1285), the advances in medical care for individuals with DS resulted in remarkable improvements in the quality of life of such individuals. Similar sentiments were shared by Christianson et al. (2006:18), who also asserted that medical care for individuals with DS requires an organized approach of assessment, monitoring and vigilance. They further highlighted that treatment for

individuals with DS includes cardiac evaluation with treatment if necessary, prompt treatment of infection, regular dental care, monitoring of thyroid function and treatment of hypothyroidism when indicated and prevention of obesity.

#### 4.3.1.3 Genetic counseling services

The genetic counseling service as indicated earlier is a relatively new service in the field of medical genetics (Christianson & Modell, 2004:237). According to the online newsletter known as the *Down Syndrome South Africa* (DSSA) (2016), genetic counseling is an invaluable service offered to individuals and families who have or who are at risk of having a genetic condition, either personally or a child with a genetic disorder. With reference to DS, genetic counselling as a medical service comes into play at two different stages, namely, prenatal and postnatal (Harper, 2004:12). On the one hand, the prenatal stage genetic counseling deals with the risk of having a child with DS in relation to the family history, the mother's age and results of medical genetic screening (Harper, 2004:12; DSSA, 2016). At this stage, the objective of genetic counseling is to empower individuals and their families with accurate information and psychosocial support (Harper, 2004:12). On the other hand, the post-natal genetic counselling deals with the management of the actual risk of having a child with DS, with the aim of enabling individuals and family to make informed decisions about the most suitable course of action to follow which may either be to terminate the affected pregnancy or to proceed with the pregnancy being aware of the associated implications (Harper, 2004:14; DSSA, 2016). In this case, an examination and chromosome analysis is performed, or parents are provided with counselling on a confirmed result for DS (Harper, 2004:14; DSSA, 2016). The clarification of the diagnosis, the cause, clinical features, prognosis, treatment options and risks for future pregnancies are discussed with parents and the necessary referrals are made (Harper, 2004:15; DSSA, 2016). As it has been indicated earlier, the social worker has a role to play in the provision of genetic counselling. The social worker can empower the parents through communication skills and linking them with the available resources in their area.

It is worth noting that the convention on the rights of the child and the South African constitution, Act (108 of 1996) guarantees children with disabilities, including children with DS, the right to basic health care and education. Free health care is available for

all children under the age of six (6) years in South Africa (Constitution of the Republic of South Africa Act, No. 108 of 1996). Adults and children with a disability are also eligible for free health care according to the Constitution. With regard to welfare and social security, a care dependency grant is available for children with disabilities needing care and support, including children with DS from the age of one (1) year to eighteen (18) years (Social Assistance Act, No 59 of 1992). The Social Assistance Act guarantees that from the age of 18, a care dependency grant is converted to a permanent disability grant.

This section discussed the management, treatment, care and support for children with DS in relation to available genetic services. The discussion has shown that the DS condition can be managed and the life expectancy of affected children prolonged with availability and access to the various medical and therapeutic interventions. However, it has become clear that despite the confirmed need, access to these services is limited to academic hospitals situated in urban centres while rural areas do not have the services. Furthermore, the introduction of a specialised team of genetic counsellors seems to complicate the situation further, given that these specialised counsellors are also not widely available. They are also available at the academic hospitals. Thus, the researcher concluded that social workers in health care settings may play a vital role if roped in to work collaboratively with these teams, given the challenge of limited and scarce resources. Social workers in health care settings may assist in expanding the services in areas that are not covered if given the necessary training in genetic counselling. The next section deals stress as an implications of raising a child with DS.

#### **4.3.2 The implications of raising a child with DS, with specific reference to stress**

As indicated earlier, raising a child with DS is an emotionally loaded experience. It is therefore expected that the families raising children with DS will be subjected to heightened stress levels driven by unbearable demands and pressures that come with raising a child with DS. The following section provides a general discussion of stress as a psychosocial phenomenon, its varied reactions and coping strategies. The literature has shown that giving birth to a child with DS evokes stressful and at times traumatic reactions leading to a state of psychosocial turmoil for the individuals and families involved (Cowles, 2000:13). Furthermore, Rosenkranz (2004) reported numerous

anecdotal incidents where a series of gross neglect and abuse of children with DS and/or other condition accompanied by intellectual disabilities occurred amongst African families in South Africa. This points to the issue of stigma that exists in addition to the already prevailing stress reactions associated with a sense of loss experienced when families have to deal with the actual or perceived loss of hope brought about by the birth of a child with DS thwarting their expectations for a normal child. Therefore, stressful reactions are to be expected amongst African families raising children with DS.

#### 4.3.2.1 Making sense of stress reactions

Before delving deeper into a discussion on stress, it is important for the researcher to start by defining what is meant by the concept stress. Stress as a psychosocial phenomenon refers to the physiological, psychological, emotional and behavioral response to internal and external demands or pressures (Van der Merwe, 2004:13). This implies that stress denotes variable responses or reactions to some form of pressure, often disruptive exerted on a person or group of people in a family system from an incident in the immediate psychological or social environment (Aldwin, 2007:6). Hence Suresh (2008:482) argues that the study of stress centers around two significant and interdependent processes of appraisal and coping with pressures exerted from the environment. The disruptive incident and the subsequent stress reactions may alter the state of equilibrium of the person or family system affected (Van der Merwe, 2004:13).

Thus, the ecosystems theory provides an effective analytic lens through which the stress phenomenon and its pertinent manifestations can be better illuminated. According to Van der Merwe (2004:14) the concept 'stress' is defined differently depending on one's discipline. He argues that in psychological terms, the concept 'stress' is used solely to refer to the psychological (mind and soul/emotions) pressures or demands exerted on the body. However, in the broader social sciences, the utility of the concept is extended to cover anything that causes impairment and instability in the balance and/or homeostasis of the body (Van der Merwe, 2004:14). A similar sentiment is shared by Suresh (2008:482).

In addition to disciplinary differences in making sense of stress, there seems to also exist considerable differences amongst individuals experiencing stress (Ross & Deverell, 2004:302). These authors argue that because individuals differ in the way they perceive things, a situation may appear stressful to one, but simply challenging to another (Ross & Deverell, 2004:302). In this sense, stress can be additionally defined as the psychological and physiological reaction to certain life events or situations (Aamodt, 2004:474). In contrast to the afore mentioned definitions Kinman and Jones (2005:101) postulate that a proper analysis of stress should break it up into the appraisals made of environmental demands, and the resources available to cope with the said demands. They go further to state that these demands should be made separate from individual responses to them, when attempting to define “stress”. Indeed, Kinman and Jones’s (2005:101) analysis of stress offers us an interesting angle from which to understand the phenomenon better. It is particularly useful in explaining the varied reactions of persons experiencing the same nature of demands with perceived similar capabilities and resources. The notion of appraisals is critical in understanding how people react to pressures exerted on them by environmental demands. A negative or positive appraisal will determine how a person deals with a stressful situation, regardless of whether they have the capacity or resources to deal with it.

The definition of stress as described above included the conceptualization of stress as a reaction as stated by Van der Merwe (2004:24). It is in this way that the body and the mind are affected by these external and internal pressures (the birth of a child with DS and the perceptions of such birth in the minds of family members). In this stress reaction, the senses of the body, such as sight, smell, hearing, touch, taste, and intuition, perceive the triggering stressor (for example;, the birth of a child with DS), and a message of danger is sent to the limbic centre, pituitary glands and hypothalamus of the brain (Suresh, 2008:484). From the brain, hormones and neural messengers are sent into the bloodstream. The body’s response to this is to secrete adrenalin, noradrenalin and cortisol from the adrenal glands, and as a result, the major organs, as well as the muscles become prepared for the fight or flight response (Suresh, 2008:484).

On the basis of the aforementioned definitions of stress, the researcher makes numerous deductions as part of making sense of stress reactions. Firstly, that stress is a fact of life and, as such, it is a normal human phenomenon. It is a clearly undisputable fact that in the course of life, we are bound to confront or be confronted with life challenges that place demands on us, leading to stress reactions of varying magnitudes. The notions of homeostasis and equilibrium relates to when the capacity within one is sufficient to accommodate the demand placed upon one. While, stress reactions are viewed as occurring when there is lack of homeostasis and a state of disequilibrium (Hudson, Moffett & McCabe, 2015:33).

Secondly, stress may either manifest positively or negatively depending on how people handle the demands (the stressors) from the environment exerting pressure on them (Hudson et al., 2015:33; Aldwin, 2007:7). When the people experiencing these stressors are unable to handle them appropriately, the stress becomes negative (for example, a family member's inability to accept a child with DS/disability), but conversely, if they manage to handle the stressors well, the experience of stress becomes positive. The demands are placed upon one's capacities. It is in the scope of one's capacities and resources at their disposal to deal with these demands that dictate how well one responds to the demands, and thus determines whether the stress experienced can be seen in a positive or a negative light. Demands placed upon the body and mind will vary from situation to situation, as will the capacities present in the person experiencing these demands. It may even be reasonably concluded that the same person experiencing the same demands at different times, such as various times in a single year, may respond to these demands differently as their capacities vary from time to time. For instance, the African family raising a child with DS may react differently to the experience of raising a child with DS before and/or after receiving psychosocial support in this regard.

The third deduction regarding stress, is that it is not the actual events, nor the person's capacities and resources or lack thereof which determine whether one is stressed or not, but rather the manner of appraisal to the stressor as argued by Kinman and Jones (2005:101). In this way, stress can be seen as a function of an individual's or in this case, the family's appraisal of a stressful situation. People do not necessarily respond to a stimulus the same way because they are, in fact, responding to the meaning they

ascribe to the stimulus. This is why people react to these stimuli differently. Thus it is not necessarily the events or conditions in the environment that are in their own essence stressful, but the perception of them by the infidel as stressful that induces the stress reaction. Meaning that it is not necessarily the birth of a child with DS that is stressful, but the perception of the family about the meaning attached to having a child with DS.

Additionally, Ambrosino et al. (2008:217) introduced the notion of the 'social stress' to extend our understanding of stress beyond the personal thoughts and emotions. The social stress perspective emphasizes the relationship between the environmental stress and mental health. This perspective suggests that individuals who are under duress including the poor, people of colour, and women are more likely to develop mental health problems. The African families raising children with DS fall under this category and therefore their experience of dealing with the challenge of raising a child with DS can be viewed as a double blow in addition to their inherent existential social conditions predisposing them to stress and mental health problems.

#### 4.3.2.2 Coping with stress reactions

As indicated by Hudson et al. (2015:33), stress is an unavoidable part of every person's life and, as such, should be managed in a positive manner. The following section will highlight the coping strategies that may be employed by African families when dealing with stress as well as the cognitive approach to coping with stress. The cognitive approach can be divided into solution-focused and emotion-focused coping, as well as the activities that go hand in hand with these coping methods (Aldwin, 2007:59). This section illustrates how relevant and congruent social work support services may aid in coping with stress experienced by African families, especially the family raising children with DS.

Coping strategies, employed by individuals for the purposes of dealing with stress can be defined as any effort, healthy or unhealthy, conscious or unconscious, to prevent, eliminate or weaken stressors, or to tolerate their effects in the least hurtful manner (Hudson et al., 2015:35). Within the context of the African family, coping can be seen as being part of the transaction that takes place between the family and the

environment where that transaction is appraised to be stressful such as the birth of a child with DS. Within this transactional framework, coping can be seen as being an integral part of the appraisal process. This process reflects the importance of the relationship the family has with the environment. Coping can be defined as managing demands that have been appraised as taxing or exceeding the resources of the family (Suresh, 2008:480; Aldwin, 2007:115). In the context of this study, coping involves efforts to manage internal and external demands and conflicts on the part of the African family. Coping strategies thus involve a complex process of thoughts and actions on the part of the family (Aldwin, 2007:116).

The following discussion focuses on the cognitive approach to coping with stress. The cognitive approach to coping with stress is based on several premises regarding the person or group, the environment and coping (Hudson et al., 2015:35; Aldwin, 2007:114). The first of these is that the manner in which the person or family copes with stress depends on the manner in which the family would have appraised a stressful situation, whether they evaluate this situation as benign, threatening or challenging (Aldwin, 2007:115). Threatening situations will evoke attempts to solve or ward off the problem, whereas a situation that involves harm or loss will evoke reactions of trying to decrease the negative emotions evoked by the stressor (Aldwin, 2007:115).

The cognitive approach also assumes that the individual or family experiencing stress is flexible with regard to their coping strategies, and can adapt and modify these strategies as the demands of the stressors change (Aldwin, 2007:115). This implies that coping is not a uniform, static activity, but rather one that changes from person to person, as well as from stressor to stressor, and from environment to environment. In supporting of what has been indicated by Kinman and Jones (2005:101), Hudson et al. (2015:36) is guided by the transactional model of stress divided coping into two distinct categories: solution-focused coping, and emotion-focused coping, both of which are discussed in the next section.

- Solution-focused coping

The social constructionist perspective of reality highlights that the reality we experience around us is 'invented' and we assimilate and accommodate new knowledge from the environment to invent it (Andrews, 2012:41). In essence, this means that when we come across new experiences and new knowledge, we are affected and changed by such encounters and make necessary modifications to adapt accordingly. In line with the social constructionist view, people collectively construct their social realities at personal or individual level in line with the social constructivist view. In light of this, stress can be seen as something which is created by the family collectively and individual members at a personal level, as they attach meaning to certain emotions, thoughts and behaviors (Kinman & Jones, 2005:101). These authors argue that when a stressor is "constructed", it challenges the abilities people have to deal with it. Meaning that when the stress is too great, its construction overwhelms people's abilities, and senses of competence and reliability are undermined. These then need to be renegotiated, in order to accommodate this stressful experience. On the basis of the above illustration, solution-focused coping involves making concerted efforts to change or manage conditions that are viewed as the source or driving force behind the stress (Kinman & Jones, 2005:101). In the following sections, the cognitive process involved in solution-focused coping is discussed.

One of the first steps in the solution-focused coping process is to begin with a "narrative" account of the stressful experience (Kinman & Jones, 2005:101). For example, as the African family raising a child with DS gives their own version of events about DS, they can begin to decipher which version of their story, with regard to the stressful experience, is the more accurate, as there will be several versions or perspectives of events. This process of differentiation, and then integration of a truer, more useful narrative, can help the African family form a less subjective perception of the problem (Knight, 2005:155). Through this narrative process, the family can perceive new options or alternatives with regard to developing an actual solution to the stressor or problem.

The next step in the solution-focused process is to track down, or list, the possible causes or origins of the problem itself (Kinman & Jones, 2005:107). This means that the person or family encountering a stressful situation will contemplate possible causal factors to the situation at hand. According to Kinman and Jones (2005:108), the ability

to pin it down to a cause is necessary for the individual encountering stress to figure out a solution without which it will be impossible to begin contemplating a possible solution to the stressor. The authors further emphasise the importance of present and past experiences and their influence on how the current situation is understood. In other words, it is crucial that in moments of difficulty, one is able to take stock of a repository of past experiences so as to guide the manner in which they deal with current and future challenges. Following Aldwin's argument (2007:115), such recollection of past experiences and the manner in which they were dealt with will not only help them determine the causes of their stress, but also help them locate or identify a path towards a solution. In the case of DS, the exploration of the cause of the problem may range from contemplating the cause of the condition itself, that is, the cause of DS to the various stressors that arise with raising a child with DS. An understanding of a cause should be logically followed by an exploration of what can be done to ameliorate the problem in line with an appreciation of the origin of such a problem (Aldwin, 2007:116). For instance, if the cause is understood to be beyond one's control, then the family can work towards accepting the problem as beyond its control and work towards coming to terms with and adapting to the new situation.

The third step in the solution-focused process is the reassessment of self-image (Kinman & Jones, 2005:111). This step has to do with the new image generated by the stressful situation. According to Aldwin (2007:116) stress in this regard is viewed as arising from a disparity in the way the individual or family views itself and the manner in which they would like to be viewed by others. This illustrates the conflict between the ordinary self and the idealised self (Aldwin, 2007:116). Aldwin further argues that the disparity between the ordinary self and the idealized self may evoke feelings of guilt, self-blame and anxiety. It is therefore necessary for the individual or family to be able to bring these two "selves" together. According to Kinman and Jones (2005:111), reassessment of self-image involves a thorough exploration of the inner perception of self-image in relation to how the outer world perceives them. In this way the individual or family concerned can begin making links to own inner perception of self-image and the consequences this perception has on the outer world. In this manner, the presenting problem or stressor is given a social or environmental context by the individual or family. This context can be used to work towards a solution to the problem (Kinman & Jones, 2005:111).

The above discussion on solution-focused coping as a theoretical framework for understanding stress reactions shed-light on one possible way of coping with stress which African families raising children with DS may use or follow when managing stress reaction emanating from their experiences. The three steps in this framework namely; “narrative” account of the stressful experience, making sense of the possible causes or origins of the problem and the reassessment of self-image may become a common process followed by the families. Therefore it is important that such a process is understood so that the researcher is able to identify typical reactions and explain them. The solution-focused coping strategies are task-oriented and aimed at dealing with practical challenges and finding solutions to such challenges. As such, solution-focused coping addresses one crucial aspect of coping relating to practical problems presented by the stressor. It does not address the emotional issues triggered by the stressor. Having dealt with the solution-focused coping strategies, the discussion will now move on to emotion-focused coping which is concerned with emotional challenges emanating from the stressful situation.

- Emotion-focused coping

According to Aldwin (2007:116), emotions can be defined as “complex psycho-physiological reactions, consisting of cognitive appraisals, action responses and patterned somatic reactions”. Within the realm of emotion-focused coping, the individual or family is faced with a potential stressor experienced within its environment, and appraisal takes place (Aldwin, 2007:116; Kinman & Jones, 2005:113). The nature of the appraisal of the stressor as argued by Kinman and Jones (2005:113) will give the individual or family a perception of the severity of the perceived stressor. The authors further argue that when the appraisal is made, emotions are experienced with regard to the stressor. Depending on the severity of the said emotions, the individual or family will attempt to cope with the stressor. While solution-focused coping focused on changing or altering the environment in response to the stressor, emotion-focused coping involves efforts to regulate or manage stressful emotions by using mechanisms that avoid direct contact with sources of stress (Aldwin, 2007:117). Thus, the researcher views emotion-focused coping as having negative and positive elements with which the individual or family may use consciously or

unconsciously, in the hope of reducing or combating stress. In this vein of attempting to manage the experienced distress, several forms of emotion-focused coping become evident. These can be split up into two main groups: those that deploy attention away from or towards the stressor, and those that attempt to change the meaning of the transaction with the environment (Aldwin, 2007: 117; Kinman & Jones, 2005:113). These main groups of coping are discussed as follows:

➤ Strategies to turn attention away from the stressor

This is also known as the “avoidant” coping strategies (Aldwin, 2007:117). This is said to be one of the most common forms of emotion-focused coping. Through avoidance, the individual or family attempts to separate themselves from the source of distress (Aldwin, 2007:117). Amongst other examples to achieve the above may include taking vacations or taking up hobbies or giving up the child for adoption or institutionalization. These attempts serve to reduce stress and improve one’s emotional state (Kinman & Jones, 2005:114). Another sub-category of avoidant coping strategies is known as “escape-avoidance” (Aldwin, 2007:117). By employing escape-avoidance, the person or family dealing with a stressful situation attempts to escape from the stress through efforts such as wishful thinking, recreational drugs, medication, smoking and drinking (Aldwin, 2007:118). Although this form of coping may provide the individual with a short lived solution or respite from the stress, these tactics are often associated with ongoing anxiety or depression, and do not prove to be successful in the long run (Kinman & Jones, 2005:114).

➤ Strategies to turn attention towards the stressor

This is another emotion-focused method of coping where attention is directed toward the stressor. The coping strategy under this category is known as ‘vigilance’ (Aldwin, 2007:117). ‘Vigilance’ is an attempt by the person or family dealing with stress to direct attention towards the offending stressor in an attempt to prevent or control it (Aldwin, 2007:118). According to Kinman and Jones (2005:114), ‘vigilance’ can include seeking help from others about the problem, as well as formulating a plan to deal with the problem. This in the researcher’s view can be a positive coping method in the sense that it can provide the individual or family with a greater understanding of the stressor

itself, and thus a greater sense of control over it. Kinman and Jones (2005:114) argue that 'vigilance' can also have negative ramifications for the person or family as it may intensify the emotional distress related to the problem by elucidating its true severity for the individual or family.

- Strategies aiming to change the meaning ascribed to interaction with the environment

This group of emotion-focused coping strategies aims at attempting to change the meaning ascribed to the transaction with the environment (Aldwin, 2007:118). According to Park (2010:265), the concept of meaning-making is key to this group of emotion-focused coping strategies. In relation to this, Park (2010:265) argues that the main object in meaning-making is the assessment of the degree to which there is (or there is not) a discrepancy between the situational meaning made of a particular life event, that is (appraisals and re-appraisals of the event and its significance or meaning) and one's sense of global meaning, that is (overall beliefs, goals and worldviews). The first category of these types of strategies is 'distancing' (Aldwin, 2007:118). Through distancing, the individual or family acknowledges the stressful problem, but does not attempt to deal with its emotional significance. In this way, distancing can be useful in aiding people in times of severe emotional crisis (Kinman & Jones, 2005:114). The above authors argue that distancing can be used as a tool in situations where there are no real options but to experience the distress, such as a waiting period associated with hearing the results of a diagnostic test. The authors also argue that distancing can help the individual or family function whilst experiencing stress that cannot be changed or altered. It is the researcher's view that this coping strategy may be powerful, but it is in fact a distortion of reality experienced by an individual or the family. Thus, the distortion may not be sustained as the environment may serve to remind the person or family of the significance of the stressful situation, and reintegrate this stress into the family's frame of reference.

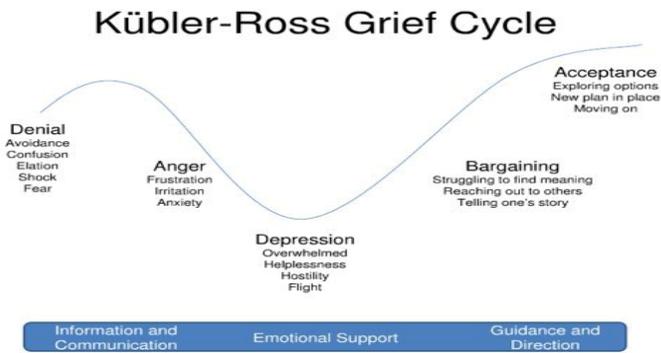
Another category of emotion-focused coping within this realm is known as 'positive reappraisal' (Aldwin, 2007:118). Positive reappraisal is used to create positive meaning from stressful results that have already occurred (Aldwin, 2007:118). This form of coping can help the individual or family come to terms with life events that are

perceived to be very severe or crisis causing. Whilst positive reappraisal can generate positive emotions such as satisfaction or pride, it can also reduce the negative effects of emotions such as fear, anger and sadness (Kinamn & Jones, 2005:115). A good example is the appraisal of the birth of a child with DS as a gift from God. While it is capable of calming the emotions, it may also evoke feelings of sadness and anger towards God when the individual or family starts questioning: why them?

In conclusion, the emotion-focused coping strategies represent ways in which people dealing with a particular stressful situation address the emotional aspects of the stressful reaction. The emotion-focused coping as a theoretical framework for understanding coping with stress illuminated various strategies that may be employed to mitigate negative emotional reactions and such. It includes strategies that deploy attention away from or towards the stressor, and those that attempt to change the meaning of the stressor or transaction with the stressor. The use of any of the above strategies will eventually ameliorate negative emotions and provide some respite for the affected individuals or families. Most importantly, both the solution-focused and emotion-focused coping are complimentary and not mutually exclusive. Therefore, in the case of African families raising children with DS, it can be expected that the family members will have to contend with both practical and emotional challenges arising out of raising a child with DS and therefore the illumination provided by the two frameworks for understanding coping with stress comes handy. The next section will consider the implications of raising a child with DS in relation to the concomitant process of grieving.

#### **4.3.3 The implications of raising a child with DS with reference to grieving**

The following section provides a discussion on the grieving process adapted from the seminal contribution made by Kübler-Ross's (1969) grieving process on 'Death and Dying'. The grieving process is useful for the researcher in understanding how African families raising children with DS could deal with the process of coming to terms with the loss of a dream for a normal child. Kübler-Ross (1969) developed a five-stage model for understanding the grieving process. The researcher is of the view that, similar principles behind these stages can be used to understand the way in which people cope with different traumatic events and losses in their lives, including how families cope with the birth of a child with disabilities such as those accompanying DS.



**Figure 2. Based on the Grief Cycle model first published On Death & Dying, Elisabeth Kübler-Ross, 1969. Interpretation by Alan Chapman 2006-2013.**

#### Stage 1: Denial and Isolation

The first reaction according to Kübler-Ross following receipt of bad news is denial and isolation (Stillion & Attig, 2015:93; Weng, 2013:11; Sanchez, 2007:6). According to Chapman (2013), denial and isolation occurs as a reaction to the bad news and it signifies denial of the reality of the situation. The above author argues that it is a normal reaction to rationalize overwhelming emotions and used as a defense mechanism that buffers the immediate shock (Chapman, 2013). Interestingly, Stillion and Attig (2015:93) argue that denial functions as a buffer after the unexpected shocking news allowing an individual to collect and compose him/herself so that with time, they may mobilize resources in defense. It is said to be a temporary response that carries the individual or family through the first wave of pain (Weng, 2013:11). Put differently, denial can be conceptualised as a conscious or unconscious refusal to accept facts, information, reality related to the situation concerned (Chapman, 2013). In the case of African families raising a child with DS, the family may deny the medical facts given to them by the medical team about DS either on the basis of a clinical or diagnostic test results confirming that the child has DS. The family may resort to different forms of denial at a practical level by refusing to accept that the child has disabilities requiring some special arrangements to accommodate the disability and an emotional level where they either avoid contact with the disability or confront the disability as non-existent or even move to alter their perceptions of the nature of disability before them. As shown earlier, anecdotal evidence shared by Rosenkranz (2004) revealed shocking, tragic and extreme forms of denial amongst some African families fuelled by stigma wherein children with disabilities are chained and locked

away in houses so that the existence of a child with disabilities in the family is not exposed to the community.

### Stage 2: Anger

The second stage of anger is said to take different forms and manifest in different ways (Stillion & Attig, 2015:93; Chapman, 2013; Weng, 2013:11). This is the substituting stage to denial (Sanchez, 2007:5). According to Chapman (2013), individuals and families experiencing this stage of the grieving process may be angry with themselves, and/or with others, especially those close to them. Building on the first stage of denial and isolation with its masking effects which eventually wear off to allow reality and its associated pain to sink in, once the individual or family begins confronting the real situation, emotional reactions follow (Sanchez, 2007:5). Often, the individual or family is not ready to deal with the demands of the situation at hand. Consequently, the intense emotion is deflected from their vulnerable core, redirected and expressed instead as anger (Chapman, 2013). The anger may be aimed at inanimate objects, complete strangers, friends or family. For instance, the doctor who diagnosed the illness and was unable to cure the disease might become a convenient target (Chapman, 2013). According to Weng (2013:12) some people may vent their anger by expressing their frustrations which may include the use of abusive and sarcastic language. In the case of African families raising a child with DS, the family may drift towards anger once realizing that the denial and isolation strategy is not sustainable. Eventually, people get to know that the child has DS and the family itself get to face the reality that indeed, the child has disabilities when any form of avoidance, distortion of reality prove futile. The family may direct its anger towards itself, others linked to the experience or even to God or ancestors. These reactions should therefore be understood within the context of the grieving process instead of seeing them as an end in themselves.

### Stage 3: Bargaining

The stage of anger is followed by bargaining (Stillion & Attig, 2015:93; Weng: 2013:11; Sanchez, 2007:6). Here the normal reaction to feelings of helplessness and vulnerability is followed by a need to regain control (Stillion & Attig, 2015:93). Secretly,

the individual or family of a child with DS may make a deal with God or their higher power in an attempt to postpone the inevitable (Sanchez, 2007:4). This is a temporary and weaker line of defense to protect them from the painful reality (Stillion & Attig, 2015:93). Traditionally, the bargaining stage for people facing permanent loss such as the loss of an expected normal child may involve attempting to bargain with God in line with the family's belief system as argued by (Stillion & Attig, 2015:93). This stage allows the individual or family to eventually find something that they can hold onto such as gratitude for the gift of a child from God regardless of the disability (Sanchez, 2007:4). Some may even bargain on their faith and hope that if they take good care of the needy child with DS, God will reward them richly and compensate for their pain and loss in some way or another.

#### Stage 4: Depression

Having bargained and found something to hold onto, such settlement does not go without emotional reactions. The emotional reactions to the settlement culminate into a depressive episode (Stillion & Attig, 2015:93). This depressive episode is also known as preparatory grieving (Stillion & Attig, 2015:93). According to Chapman (2013) preparatory grieving represents the dress rehearsal or the practice run for the 'aftermath' although this stage means different things depending on whom it involves. It's a sort of acceptance with emotional attachment. Chapman (2013) postulates that there are two types of depression associated with grieving or mourning to loss. The first one is a reaction to practical implications relating to the loss. Sadness and regret pre-dominate this type of depression (Chapman, 2013). The family will for instance worry about the financial and emotional costs of raising a child with DS. The second type of depression is more subtle and, in a sense, perhaps more private (Chapman, 2013). It is associated with the family's quiet preparation to let go of their preconceived hopes, fantasies and plans that might have been prepared for a normal child.

#### Stage 5: Acceptance

The final and last state is called acceptance (Stillion & Attig, 2015:93; Weng, 2013:11; Sanchez, 2007:6). This phase is marked by withdrawal and calm (Stillion & Attig, 2015:93). The stage of acceptance varies according to the family's situation. At this

stage, it is broadly accepted that there is some emotional detachment from the loss and there is some level of objectivity (Stillion & Attig, 2015:93; Weng, 2013:12). The family of a child with DS eventually comes to accept both the reality of a child with DS and seeks solutions to manage the condition the best way they can. At an emotional level, the family lets go of all sort of denial and distortions and accept the pain and loss so that they move on with a sense of emotional easiness. The family begins to objectively appreciate the reality of positive and negative spinoffs from the experience and deals with them as they come without resorting to any form of distortions.

In summary, this section covered a discussion on stress reactions and the grieving process. The discussion on stress reactions and its associated coping strategies showed that individuals and families will react differently to stressful situations. Such stress reactions may be effectively contained or worsened depending on how they are appraised. The appraisal depends on the individual or family's capacity to deal with the demands of the stressful situation. Better capacity leads to better coping whereas lack of capacity may lead to more overwhelming degrees of stress reactions. Sometimes, negative appraisal may be attributed to lack of information. Additionally, the use of Kübler-Ross's grieving process illuminated better understanding of the grieving process that individuals or families may go through following an experience of loss as they attempt to come to terms with the loss. Therefore, the ability or capacity of the family to access accurate information may hold the key to better coping. However, dealing with accurate information requires that one is emotionally stable to contain such information. Therefore, social support is important throughout in order to assist with appraisals, provide tangible support including both practical aid and provision of needed information. Having dealt with the stress reaction and the grieving process, the researcher now moves to analyze the nature of contemporary social work services in South Africa.

#### **4.4 Contemporary South African social work practice and health behaviors of Africans.**

As discussed earlier, the unique African context characterized by a different worldview and cultural thought from the dominant Euro-North American one means that social work practice in Africa should be decolonized and indigenized to achieve relevance and responsiveness. The following section maps out the landscape of contemporary social work practice in South Africa. The discussion is followed by an exploration of some of the typical health behaviors of Africans. It is important to juxtapose contemporary social work practice in South Africa against typical African practices and behaviors so as to highlight areas of possible dis-junctures, gaps and synergies that this study attempts to address.

##### **4.4.1 Contemporary social work practice in South Africa**

From its inception in the 1930s, social work in South Africa was based on a clinical approach and a treatment-oriented emphasis of intervention focusing on case and group work undergirded by a residual welfare system (Smith, 2008:374). The researcher argues that a turning point in the South African social work fraternity came with the post-1994 political transition, which ushered a new developmental welfare system with concomitant changes in the conceptualisation of social work training and practice.

Elucidating these changes, Patel (2011:214) defined developmental social welfare as a “pro-poor strategy promoting participation of the socially excluded in development activities to achieve social and economic justice, a partnership approach to social development, social solidarity and active social citizenship”. This approach is anchored by five key elements which are: rights-based approach, economic and social development, democracy and participation, social development partnerships and bridging the micro and macro divide (Patel, 2011:215). The developmental welfare system highlighted the critical need for community development supported by the White Paper for Social Welfare (Department of Welfare and Population Development, 1997:15) making it a focal area for social work training institutions. The above sentiments are echoed by Patel, Schimid and Hotchfeld (2012:215) in their

review of the developmental welfare system in South Africa when they highlighted that “[within the developmental welfare]...a generalist social work practice is favored that is family/household-centred and community based”. The question is whether this shift has been successful or not particularly in practice. Its successful implementation in practice would mean that African families raising children with DS would receive social work services focusing on empowerment, that are non-remedial in nature, interventions that are concerned with participation and people’s networks, as well as interventions that are concerned with economic development and independence. It is worth considering that the prime goal of the social work profession is to promote social development, social change, social justice, empowerment and liberation (Sewpaul & Jones, 2004:100).

To this end, contemporary social work adopts a human rights perspective which reinforces the social work profession’s belief in the worth and dignity of all human beings and their inherent capacity for purposeful change. It is against this backdrop that the researcher deduces, therefore, that contemporary social work is indeed alive to the fact that social, cultural, economic, political and environmental conditions can impact negatively on human well-being. Accordingly, one would expect that the African families receiving social work services will benefit greatly from the developmental approach (as expounded above) as well as a holistic approach to needs and social problems that take into account the social, cultural, economic, political and environmental conditions.

On the basis of the above assertions, it is crucial that the theory and practice of social work be foregrounded on an appreciation of both universal as well as indigenous knowledge systems. In the spirit of the sentiments expressed by Sewpaul and Holscher (2004:100), the contemporary social work scholars “...have the power of criticism, and must not, in the name of objectivity and science, distance themselves from the power relations that exclude, oppress, subjugate, exploit and diminish other human beings”. As cautioned by Ledwith (2001:171), “the political nature of education either situates educators as agents of the state or as agents of transformative change: either perpetuating the status quo or creating the context to question.” In this regard, Patel (2005:370) maintains that it is essential that new graduates are critical thinkers with reflexive competence in order to respond to new realities in new ways.

The South African social work education fraternity undertook a review process under the banner of the Council for Higher Education (2004:15) aimed at determining what an appropriate level of preparation of contemporary social workers should be for the South African context through publishing the Standards Generating Body. Through this review process, learning outcomes for social work training were identified and implemented by institutions of higher learning offering social work training. A major outcome of the review process was the twenty seven (27) exit level outcomes (ELOs) which identified key competencies and skills that a social worker should have acquired at the end of their bachelor's degree in social work in relation to social work interventions, administration and management (CHE, 2004:16).

It is against this backdrop and, as the researcher observed, that contemporary South African social work is anchored by a comprehensive theoretical base. This theoretical base is tailored to provide social work with a knowledge system offering a frame of reference for the profession in line with present day socio-economic challenges. The theoretical knowledge base is made up of a repertoire of theories used to explain and manage social problems. However, the researcher has observed that despite many advances made in the profession and its practice, the theoretical knowledge base remains Euro-North American in content and form—to the exclusion of Afrocentric knowledge systems.

A thorough analysis of the theoretical knowledge system of social work by the researcher enabled him to categorize them into three areas: (i) theories that illuminate our understanding of people, situations and events; (ii) theories that analyse the role, task and purpose of social work; and (iii) theories that relate to direct practice, such as practice approaches and perspectives. Depending on one's ideological and paradigmatic positionality, a rich repository of theories that illuminate our understanding of people, situations and events exist and can be filtered further into consistent and coherent categories. Often the categories compete with one another according to established usefulness and other benefits inherently associated with each category. However, one must also highlight the limitations linked to how the theories are applied and the glaring omission of other equally important cognate disciplines such as African anthropology, archeology, history, philosophy, politics and ethnic

studies. The researcher notes with concern the fact that the theoretical knowledge base of social work is foregrounded on foreign cultural orientations and thoughts much to the exclusion of the African cultural thought. The limited application and omissions can be attributed to the hegemonic discourse undergirding social sciences and social work in particular linked to Eurocentrism and its concomitant coloniality and imperialism. As it shall be seen with the unfolding discussion, the one thread that cuts across all of them is their foregrounding on liberal, individualistic western orientation with a patriarchal and racist character. Writing from a vantage point of an African, the researcher views the omission of the African experience in all of the theoretical constructs as one grave concern that calls for urgent redress.

On the basis of the above critique of the conventional theoretical knowledge system, it is therefore imperative that social workers in all spheres of practice, education and research in Africa take a paradigm shift, not only from a remedial orientation dominated primarily by casework and group work, but also from the pseudo-universal construction of western indigenous theories imposed on all locales. The shift must be towards a pluriversal (multiple worldviews) body of theoretical knowledge rooted in multiple particularities of the world and a more pragmatic historic, economic and political orientation. The pluriversal view espouses the multiple worldviews and paradigms as may exist across the world as opposed to the universalist stand point that privileges one worldview/paradigm (western) as superior to all (Tlostanova & Mignolo, 2009:132).

The researcher selectively focuses on theories that analyse the role, task and purpose of social work at a theoretical level. This is because this study focused on social work practice with African families raising children with DS rather than the actual theoretical knowledge generation and education. The researcher was interested in understanding the theoretical conceptualization of the role of social work with clients and whether social workers are applying it as theorized or not. The researcher was also interested in uncovering the extent of congruency between current social work practice and the nature of the identity of African families. Therefore, the decision to focus on theories that analyse the role, task and purpose of social work stems from the unit of analysis underlying this study.

The researcher observed that the 21<sup>st</sup> century has witnessed the ushering in of new ways of thinking that challenge the conventional ways of thinking about human life and society. The new thinking shifted from an exclusive focus on individual minds and actions to embrace thinking about social structures, systems and discourses (Schatzki, 2005:50). The social work profession stands to benefit greatly from the new theories. These theories that analyse the role, task and purpose of social work essentially help social workers understand human beings and how they can be assisted. Such an understanding remains critical in developing psychosocial and therapeutic interventions. The contemporary social worker is therefore called upon to demonstrate an appreciation of theoretical issues at various levels in order to utilize such theoretical knowledge to guide his/her skilled professional interventions.

Hepworth and Larsen (2008:18) highlighted some of the critical skills required in contemporary social work as follows:

- The ability to build and sustain helping relationships.
- Ability to select appropriate mechanisms for monitoring and evaluating social work interventions.
- Awareness of the need to collaborate with other professions and disciplines and being able to function in multi-disciplinary teams.
- Awareness of the potential limitations of western theories in dealing with local realities.

The CHE (2004:16) shares similar sentiments about most of the critical skills listed above. In effect, although this has not been receiving adequate emphasis within the African social work curriculum and training, the researcher is of the view that such skills are not new to the field of social work. Emphasis on person-in-environment is simply a call on social workers to treat a person as alive in a lived social, cultural, economic and political context. The 'person-in-environment' construct suggests that social workers always examine individual behavior in its context, reflecting on how that behavior is both a response to and, in turn, influences the individual's environment. The typical example of such theoretical expectations is family and child welfare services as a field of service in social work. In effect, working with a child or adolescent requires knowledge of developmental factors and communication skills that are unique to young people. On the other end of the age spectrum, older people also have unique needs

that a social worker should recognize. In addition, the researcher argues that the emphasis placed on psychosocial support, mainly due to a precipitous social problems caused by a wave of diseases and medical conditions including DS, calls for more versatile theoretical grounding than traditionally known to the profession.

Furthermore, the African society has unique and at times complex ways of coping with social challenges as discussed under the African philosophy and worldview. The common coping strategies used by most Africans tend to take a form of spiritual and religious orientation, creating serious confusion when intersecting with the Eurocentric social work. The researcher observed during the course of his training as a social worker and currently in his engagements with teaching that such typical African practices such as spirituality and affect are not emphasized in most of the African schools of social work. The researcher reviewed the contemporary theoretical knowledge base of social work to confirm the above position and observed that social work as a profession in its history has paid little attention to religious tolerance and issues of human diversity and spirituality. Thus, the researcher contends that social work in Africa urgently needs to start investing its attention on issues of spirituality and cultural relativity.

It is crucial that we also discuss theories that relate to direct practice, including practice approaches and perspectives. The IASSW and IFSW (2014) adopted the international definition of social work as discussed earlier. As per the definition of social work, there are clear expectations requiring that social workers be versatile with a plethora of theories and knowledge systems to help shape their practice. Patel (2005:96) is of the opinion that the trend in theoretical choices in contemporary social work practice in South Africa stands in response to the call for a departure from a remedial approach to practice towards a more developmental and proactive orientation. Although the assertion by Patel is ideal and desirable, it seems not much has been done to ensure that it trickles down to practice so that there is evidence-based affirmation for the position articulated above.

Finally, the researcher reviewed literature on contemporary social work in health care settings. According to Auslander's (2001:211)'s report on the review of social work in health social work in the international arena there has been a shift from the 'disease'

paradigm (biomedical) to a social model of health (psychosocial) which takes into consideration the social, psychological, spiritual, cultural and ecological factors. Social work in health care is accordingly defined by the SACSSP (2010:16) as a specialised field in social work that focuses on the complete person, that is a bio-psychosocial being, and the person's family, immediate environments and larger social context, in trying to improve the interaction with the environment as a source of resources to address the imbalances that might have occurred due to illness or disability. The literature on social work in health care settings illuminates the role of social work as including, amongst others, soothing patients' anxiety about hospital admission, circumstances at home, forthcoming surgery or treatment, and future prognosis (Hepworth, Rooney, Rooney, Strom-Gottfried & Larsen, 2006:223; Zastrow, 2004:285). According to Cummins et al. (2006:4), social workers may utilize therapeutic skills, as well as interventions that are educational and task-oriented in nature, amongst others. Social work in health care is a significant field of practice in South Africa and is ranked second largest after welfare social work (DSD, 2016:263; Earle, 2008a:36). Social work in health care settings forms part of a list of numerous fields of specialised practices also known as social work in secondary settings or host settings (Zastrow, 2004:527). This is because the primary purpose of health care settings is to provide health care, and social work is offered as a support service complementing health care (Falck, 1978/2008:395). This has implications for practice, given that some compromises have to be made in adapting practice modes and conditions to the context which was inherently designed for health care services, not social work. Thus, some trade-ins have to be made. According to Zastrow (2004:528), the acceptance of such trade-ins as described above, relied on a confused expectation of the role of the social worker, and thus laid the groundwork for the present relationship between doctors, social workers and patients - one which still has difficulties today. It is on the basis of the above that social workers to date find it difficult to assert their professional autonomy in secondary settings such as health care.

Furthermore, Hepworth et al. (2006:228) argue that over the years, hospitals have become increasingly aware of the need to consider the social and emotional needs of patients, in addition to their physical needs, in order to offer effective treatment. This has led to the use of inter-disciplinary teams in an effort to deliver holistic care (Hepworth et al., 2006:228). The aim of the interdisciplinary team is to integrate "... the

concepts, methods and data of diverse disciplines in order to provide better health care for the individual, family, community or population” (Zastrow, 2004:259). The above author asserted the significance of seeing the patient holistically in line with the social model of health care and the concept of self-determination in relation to the nature of services offered in health care settings. The author argues that this is achieved when the social worker includes the patient and his/her family in the planning of any treatment and when decisions are made concerning his/her case. It is in this area that health care social workers make their most important contribution. The author articulates the importance of a social focus by emphasizing that illness or disability are social events that make certain demands on the lives of the individuals concerned and their significant others in the social environment.

As the hospital (or any other health care setting) is a secondary setting for the practice of social work, a medical social worker is responsible to the patient and his/her family; to the hospital itself, and also to the community in which he/she works (Zastrow, 2004:528). The latter author further emphasizes that, given that a social worker works within a multi-disciplinary team, it is essential for the social worker to have a thorough understanding of his/her profession, to know what functions he/she may fulfil, and in what ways he/she may benefit the patient as a client. The social worker may also be asked to pass on to other team members their specific knowledge and skills. Therefore, being aware of the ease with which role-blurring and role-overlapping occurs in teams is imperative (Hepworth et al., 2006:228). As such, for effective multi-disciplinary team collaboration to occur, each member of a unit such as a social worker should have a strong sense of belonging to one's profession, self-reliance coupled with interdependence, willingness among personnel to learn from one another, and the ability to work together with respect for the difference in knowledge, skills and specific objectives that characterise different professions or functions within a profession (Falck, 1978/2008:396). The helping process in social work, according to Cummins et al. (2006:5), begins with engagement and assessment. It is during this stage that the social worker engages the client on the presenting problem in order to find underlying issues that give birth to the presenting problems. Cummins et al. (2006:5) further emphasise that assessment is an on-going process in social work and social work intervention plans should take into account social systems that have an impact on social functioning in a holistic and integrated manner. Cummins et al. (2006:6)

postulate that the unique focus on the person-in-environment is one aspect that set social work apart from others as a helping profession. It is through an in-depth assessment and person-in-environment perspective that social workers are able to connect the person to significant systems and factors in his/her social environment including issues of culture.

On the basis of the above complexities of social work practice in health care, Falck (1978/2008:395) argues that despite the fact that social workers' practice in health care is influenced and guided by the setting, social workers need a clear link to their profession, its methods, theories, assumptions and values. He argues that social work in health care can only be effective if social workers display and confirm their identity by what they know and can do instead of simply allowing themselves to be directed by other professions such as the physician who is perceived to be in charge and exercises control over who works with the patient. Thus, Falck (1978/2008:396) emphasises that social workers should be sophisticated enough in their knowledge as well as political sophistication which will make them less willing to take orders from non-social workers resulting in a more equal participation by social workers in the multi-disciplinary team. It is Falck's (1978/2008:397) strongly held view that professional autonomy and collegiality is key to ensuring that social workers act independently on the basis of their knowledge and expertise instead of simply reacting to others leading to restricted and constricted practice.

In conclusion, this section discussed the landscape of contemporary social work practice in South Africa including opportunities and challenges underpinning social work as a profession. It is clear from the discussion that while a lot of progress has been made to address some of the known challenges and bring forth alternative developments, a lot still needs to be done to guarantee that solutions envisaged are implemented widely. The South African social work fraternity seems to have succeeded in transforming the broader framework of social work including policies. This has been attested to by the adoption of the developmental approach to permeate all manner and forms of social work. As highlighted by Patel (2011:215), there is no empirical evidence showing that the new developments have trickled down to define the face of social work practice at grassroots or that it is merely a political move expressed on paper, but lacking practical effect. The discussion will now proceed to

focus on the exploration of some of the typical health behaviors of Africans. This is important to appreciate in relation to the current state of social work in South Africa as it provides a context within which the contemporary social work form and content is practiced. Therefore, the discussion will seek to assess whether there is congruence at a theoretical level between the form and content of social work and the ways of life and being of Africans.

#### **4.4.2 The health behaviors of Africans and their implications for social work practice in South Africa.**

Having discussed the implications of stress and grieving on families raising children with DS as well as the contours of contemporary social work practice in South Africa, the discussion now moves on to cover common health behaviors found amongst Africans in relation to their perceptions of illnesses and their implications for social work with African families raising children with DS. The literature on the health behavior of Africans seems to suggest that the African perspective on the etiology of illness generally entails negative connotations on the basis that incidents of ill-health, disability and disease are often attributed to witchcraft and/or punishment by the ancestors for doing something wrong (Bruns, Jhazbhay, & Emsley, 2011:541; Mzimkulu & Simbayi, 2006:425). Although the researcher finds the arguments advanced by the above authors to be true of Africans, its reductionist analysis is however problematic as it leaves out equally important aspects of the lived experiences of Africans underpinned by the African worldview. Indeed, African families may attribute illness to various causes with negative and stigmatizing connotations, but they also draw inspiration and wisdom from a variety of sources beyond the limited objective account of etiologies. These include their belief in God, the creator of everything (spirituality) and intuition which enables them to deal with anything confronting them regardless of what they think might have caused it. For instance, a family with a child with DS does not decide to stop having children because one of its children has been bewitched and ended up with DS. Instead, they accept the gift and move on normally knowing that there is a God who cares.

The above situation calls for phenomenological intervention that challenges social scientists to employ descriptive and interpretive analyses of lived experiences of

Africans facing illness, disability and disease. Through this phenomenological intervention, the general negative connotations that Africans attach to incidents of ill-health, disability and disease will be better understood and used as a foundation for all theories about them. The phenomenological interventions will accordingly be followed by existentialism. Existentialism stresses the importance of attuning caregiving to the singularities of the lived experiences of unique individuals. In this case, those responsible for professional intervention geared at assisting Africans experiencing illness, disability and diseases would have to use theories founded from the lived experiences of Africans as the basis for their intervention instead of committing an error of merely and remotely parachuting theories developed somewhere else and thought to be applicable across different situations. It is the same error that led Bruns, Jhazbhay and Emsley (2011:541), as well as Mzimkulu and Simbayi (2006:425), to the conclusion they made about Africans views on illness, disability and disease.

Most importantly, it should be noted that objective knowledge still forms part of the African worldview (Schiele, 1997:812; Ani, 1994:25). The objective truth and other sources of knowledge such as spirituality and intuition/affect are not viewed as opposing/conflicting forces, but as complementary to each other. The belief in God, ancestors and spirits does not imply rejection of science, but rather that science helps human beings to understand the laws governing phenomena (health, physics, climate) created by God, giving practical expression to the complementarity view of the relationship between all the sources of knowledge (Schiele, 1997:812).

As highlighted by Penn et al. (2010:16), amongst the many deterrents to access health care of the underserved African populations, ethno-cultural barriers are among the most important. The researcher discusses the ethno-cultural barriers in the context of health behaviors of Africans. Key to typical health behaviors of Africans is their tendency to use both western and African traditional medicine as indicated by Ross (2008:16). This sentiment is echoed by Penn et al. (2010:10) who argue that traditional healing systems are widely accessed by Africans who tend to consult both western and traditional healing systems in order to improve their chances of recovery from a particular illness or condition. Ross (2008:17) states that “it is estimated that 8 out of every 10 South Africans consult with traditional healers in conjunction with or in preference to western trained medical professionals”. The World Health Organization

(WHO) classifies the traditional healer as “someone who is recognized by the community in which he lives as competent to provide health care by using vegetable, animal and mineral substances and certain other methods based on the social, cultural and religious background as well as the prevailing knowledge, attitudes and beliefs regarding physical, mental and social well-being and the causation of disease and disability in the community” (Ross, 2008:17). The researcher maintains that there are various reasons to explain this phenomenon. Firstly, African traditional medicine is indigenous, making it congruent with African people’s traditional and cultural belief systems. Secondly, it is an age-old practice that stood the test of time and has been proven to work for a sizable number of people who depend on it and have developed loyalty to it over time. Thirdly, it is believed to be cheaper and accessible. According to Keeton (cited in Ross, 2008:17) there are between 250,000 and 400,000 traditional practitioners compared with 23,000 registered medical doctors. Consequently, South African social workers need to be aware of the beliefs and practices of traditional healers in relation to health, illness, and disability as well as ways of restoring well-being (Ross, 2008:18). This also applies to African families raising children with DS. It is expected that some of them will, over and above the use of western medicine, also resort to using African traditional medicine.

In September 2004 the South African government promulgated the Traditional Health Practitioners’ Bill, which acknowledges the role that traditional healers play in South Africa. The Bill recognizes the unique circumstances of traditional healers, sets professional and ethical norms and standards and seeks to empower traditional healers to regulate their practices (Matomela, 2004). In addition, traditional healers are required to register with a statutory council to ensure regulation and strict supervision in order to prevent malpractice (Matomela, 2004). This legislation supports the stance adopted by the WHO on traditional healing in developing countries, and is likely to impact significantly on health care in this country. WHO expounded the need for social and technical training of traditional healers for their subsequent involvement in the provision of primary health care in their respective communities (Ross, 2008:18).

It is significant that Ross (2008:19) further argues that traditional healers occupy an esteemed position within South African culture as they are consulted for a wide range of physical, social, and emotional problems and that they are often expected to assume

the roles of medicine healer, priest, psychiatrist, advisor, diviner, and herbalist. Ross (2008:19) further stressed that amongst factors providing support for traditional healing amongst Africans appears to be its ties with religious beliefs. For instance, a common belief among many African cultures is that a disease can be brought on by spiritual pollution where people are considered to be ritually impure due to engaging in some activity believed to be unclean. Without knowledge of the client's cultural context, professional intervention is likely to become an intercultural collision of values, attitudes, expectations and definitions (Ross, 2008:19).

A second factor in understanding African health behavior is the influence of culture and inheritance. According to Penn et al. (2010:14), culture and inheritance have a complex relationship. Accordingly, Penn et al. (2010:14) stress that in the African cultural context, inheritance includes a different understanding of kinship which is incompatible with western models of inheritance. They cite an example that in the patrilineal kinship system, kinship and descent are traced through the paternal line and diseases may be derived from a paternal ancestor. Decision making about health is often made at the level of the family, as the family is the central organizing structure and older people in certain social and kinship positions have a very strong influence in the community (Penn et al., 2010:14).

A third factor in considering African health behavior is the critical role played by elders, particularly grandparents. As argued by Kasanga and Lwanga-Lumu (2007:67), elders hold a position of great respect both within the community and the family in many African cultures. Their role has been described in relation to teaching and bringing up children as well as playing an important role in illness (Kasanga & Lwanga-Lumu, 2007:68). In addition, Barratt and Penn (2009:195) indicate grandparents are often the first to be consulted when there is illness in the family and thus serve an important role as gatekeepers of knowledge about illness and treatment. The role and responsibilities of grandparents have been strengthened particularly in recent times, as the Aids epidemic has resulted in the death of a large number of parents (the middle generation) and a growing population of orphans. Thus, grandparents have assumed the role of primary caregivers and their state old-age pensions are often the sole source of income (Barratt & Penn, 2009:195; Bock & Johnson, 2008:135; King, 2008:109). The role of grandparents has also been demonstrated over the years with

the advent of the migrant labour system when men relocated to the cities in search of work, leaving grandmothers in leadership positions within communities (Barratt & Penn, 2009:196). Penn et al. (2010:15) noted that in line with kinship issues, the paternal grandmother seems to have particular power over her son's relationships and decisions about his children.

Fourthly, there are ethnic differences regarding autonomy, protection of confidentiality in families and a tendency towards collective decision making and a social responsibility for health (Ware, Idoko, Kaaya, Biraro, Wyatt & Agbaji, 2009:41; Port, Arnold, Kerr, Gravish & Winship, 2008:135). For example, a woman coming alone for counseling after referral is being asked to make a decision which may well be subsequently queried or challenged by the family. Therefore, a model of social decision making and social responsibility seems more compatible (Ware et al., 2009:42; Port et al., 2008:135). The implications are that when dealing with Africans, social workers need to adapt their approach so that they are able to focus more on the family in the counseling process and adopt a group rather than an individual counseling approach.

A study by Ross (2008:19) found that several African traditional healers believed that cranio-facial conditions signify that the affected individual has been identified by the ancestors to become a traditional healer and that one should therefore not interfere with the ancestor's wishes through surgical intervention. Thus it is that Ross (2008) cautioned that this belief raises ethical concerns for social workers as social workers are expected to respect the cultural beliefs of different groups; however, they also need to consider the rights of affected individuals to receive surgical intervention that could potentially enhance their quality of life. Another issue revealed in Ross' (2008:20) research is that many disorders and disabilities were perceived as a form of punishment for wrongdoings. Ross (2008:20) warned that such perceptions are likely to evoke intense feelings of guilt in parents, caregivers, and affected individuals. Therefore, in Ross' (2008:20) view the question that arises is whether social workers should simply encourage people to work through these feelings in counseling, or whether they have an ethical obligation to provide people with information on the "scientific" nature and etiology of the condition. The author maintains that such information could in fact run counter to their religious and cultural beliefs. Her personal

stance was that it is possible to provide such information in such a way that one still conveys respect for the client's cultural beliefs and values.

Thus, the issues discussed above are important for social workers to note when assisting African families as it provides a fruitful and exciting context to explore such influences on the helping process and provide ample opportunities for the development of more relevant models of intervention. Ross (2008:20) is of the view that a more open approach on the part of social workers and other health care professionals might enable clients to bring these matters into the counseling arena without fear of being judged.

Awareness of the concurrent use of medication prescribed by the western doctors and remedies provided by traditional healers could potentially alert members of the multidisciplinary health care team (which usually includes social workers) to the possible interaction effects of such treatment. Furthermore, different types of diagnosis and treatment might also affect compliance with medical regimens. Nevertheless, the potential for collaboration needs to be explored as both sectors would appear to have the same goal, namely to strive for the best outcome for the client or patient as Ross argues (2008:21).

The discussion on the health behaviors of Africans has shown that Africans tap on to various sources of knowledge when dealing with stressful experiences related to ill-health, disability and disease. Firstly, it is clear from the discussion that Africans appreciate the scientific and object explanations of illness. However, such explanation is dealt with in the context of a complex cosmology characterized by interplay of various interrelated and interdependent factors in their environment. Most importantly, it is notable that their knowledge of the world and reality is derived from spiritual and intuition/affect in addition to objective truth. Although, at times negative connotations emerge out of some of the sources of knowledge, it should not be generalized as negative given that both negative and positive outcomes may be experienced and all these form part of their existential reality. Therefore, it is important that the descriptive and interpretive analyses of the lived experiences of African families raising children with DS or facing health challenges remain a foundation for all theories about them. These should be viewed in relation to the African worldview. Indeed, African families

may attribute illness to various causes with negative and stigmatizing connotations, but they also draw inspiration and wisdom from a variety of sources beyond the limited objective account of etiologies. These include their belief in God, the creator of everything (spirituality) and intuition which enables them to deal with anything confronting them regardless of what they think might have caused it.

#### **4.5 Summary of the chapter**

This chapter presents the context of the African family as an institution, its structures and functioning. It provides a historical analysis on how the institution has been shaped and changed over time. The analysis revealed that the African family form has over the years grappled with pressures beyond its control, forcing it to change and adapt. However, the family form has shown greater resilience in retaining most of its unique characteristics despite a fierce assault on its form. A glaring example of its enduring unique trait is its extended family connections which continue to manifest in both rural and urban locations to date. The chapter also provided a discussion of DS as a medical condition as well as available specialized medical and genetic counseling services.

Analysis revealed that medical genetic services for children with DS and their families and social work remain fragmented despite many attempts at integrating them. The creation of a limited specialized genetic counselling seems to have compounded this problem as it appears to be an unnecessary duplication of services that might have otherwise been rendered by social workers or psychologists in hospitals with training on medical genetics. This was followed by a discussion on stress and the grieving process. The nature of contemporary social work practice in South Africa was also discussed. The field of social work has been undergoing major changes in the past two decades in an attempt to position it to respond better to the pressing social challenges of contemporary South African society. The chapter also covered health behaviors of Africans and their implications for social work practice in health care settings. An understanding of the typical health behaviors of African families, which is likely to be observed amongst African families raising children with DS, is important for social workers. Social workers can intervene better with this knowledge and tap into significant social resources linked to it.

## **CHAPTER FIVE**

### **PRESENTATION AND ANALYSIS OF RESEARCH FINDINGS**

#### **5.1 Introduction**

The findings presented in this chapter reveal that the conventional notion of family as made up of two conjugal partners and their children does not resonate with the lived experiences of Africans interviewed in this study. Instead, it was found that the typology and form of social organization prevalent amongst Africans interviewed in this study could be best described as a 'clan system' rather than a family system. The researcher noted that some authors when faced with the challenge relating to the above discrepancies, they opted to use the term 'traditional African family'. By superimposing the term 'traditional African family', the implication is that such a family form effectively represents a deviation from an established and superior norm of a conventional nuclear family. Thus, the researcher opted to replace the word family with 'clan'. The word clan will henceforth be used in this chapter as well as chapter 6 that presents the guidelines.

This chapter presents qualitative data collected through semi-structured interviews from African clans raising children with DS, social workers employed by the health-care settings and those working for the DSD in communities as well as the analysis thereof. The data was collected during the course of the year 2015 and 2016. As indicated in chapter one, this study was firstly prompted by an apparent lack of literature on social work services to individuals and clans raising children with DS. This is despite DS being a debilitating condition with immense negative psychosocial effects. Secondly, the lack of literature that examined the role of African tradition, cultural heritage and spirituality as a frame of reference for the African clan and the helping process created a knowledge gap in the profession and academic discipline of social work. Consequently, the aim of this study was to develop an in-depth understanding of the nature of the identity of African clans, their lived experiences, their coping mechanisms as well as their suggestions on how they could be assisted by social workers in a culturally sensitive manner while raising children with DS. Finally, it brought to view the

opinions of social workers assisting African clans regarding the level of congruence between the service they provide and the needs of the African clan.

In order to realise the above aim, the researcher obtained a sample of African clans raising children with DS as well as social workers rendering services to these clans, found in and around the provincial boundaries of Gauteng, North-West, Limpopo and Mpumalanga provinces of South Africa. Semi-structured interviews with African clans raising children with DS and focus group discussions with the biological parents and/or primary caregivers/guardians of children with DS were conducted in order to explore the nature, lived experiences, coping mechanisms and perceptions of African clans raising children with DS. Subsequently, the researcher explored their suggestions regarding how they would like to be assisted by the social workers in a culturally sensitive manner.

Furthermore, semi-structured individual interviews were conducted with social workers rendering services to African clans raising a child with DS in order to explore their opinions regarding the level of congruence between the services they provide and the needs of the African clans when raising children with DS. The data was then sifted, sorted and analysed using steps in the qualitative data process adapted from Terre Blanche et al. (2006:33). The above process culminated in the generation of themes and thematic content analysis was used to analyze and interpret data which is presented in the form of discussions around themes identified both inductively (data-driven) and deductively (theory driven).

Three theoretical frameworks, namely, social constructionism, ecosystems and strengths perspective that were used as the lens in conducting this study were used for the analysis and interpretations of forces shaping African clans. The frameworks were marshalled to elucidate the manner in which African clans make sense of their lived experiences of DS and their coping mechanisms. Given the nature of this study with its focus on African clans and their unique socio-cultural practices related to raising a child with DS and interaction with social workers, language was considered to be a very important aspect. The fact that the thesis is written in English presented a challenge as some of the English terms are not available in African languages or may have different meanings when used in the African context. The researcher thus selected to use some

of the important vernacular words from the seven (7) African languages involved in the study and provided their English translation to facilitate understanding for the reader. Conclusions regarding the implications of all findings for the indigenisation of social work practice in respect of African clans raising children with DS were then drawn. These culminated in the development of indigenous practice guidelines for social workers, ostensibly to assist African clans raising children with DS in a culturally sensitive manner that allows them to understand, own and control the help received.

The qualitative data came from interviews facilitated by the researcher with African clans raising children with DS. This was juxtaposed with qualitative data collected through semi-structured interviews with two categories of social workers, viz., social workers in health care settings (hospitals) employed by the Department of Health (DoH) and social workers practicing in communities employed by the Department of Social Development (DSD). These social workers' respective workloads would accordingly be expected to include amongst others, the rendering of assistance to the African clans raising a child with DS. The diagnosis of DS whether clinical or through a diagnostic test would have been done at a hospital facility. The hospital facility would normally have a social worker or social workers providing psychosocial support to patients and their clans. Once the child is discharged from the hospital, the clan goes back to the community where they reside. The communities are often allocated at least one or more social workers charged with the responsibility of ensuring that clans in need of psychosocial assistance for any reason are assisted. In most instances, the DSD also have a dedicated and specialised disability unit dealing with all manner of disability in communities. Therefore, it may be reasonably expected that in the normal course of events, the African clan raising a child with DS would receive assistance from both these two categories of social workers. This is the reason behind their inclusion in this study.

## **5.2 Presentation of data and analysis of findings**

The conversations with African clan members took two forms. One was a clan interview and the other was a focus group discussion and they were both semi-structured. An interview guide was used for the clan interview and focus group prompts used for the focus group discussion. The focus groups were made up of the biological

parents, who were mainly mothers or fathers and in some cases the primary caregiver who, in most instances, was a grandmother, an aunt or a sister to the child with DS. The clan members who participated in the focus group discussions came from the existing support groups facilitated by the DSA.

The conversations with members of the African clan in both instances (clan and group) focused on the nature of the African clan raising a child with DS; the recollection of African clan members regarding experiences and coping mechanisms when raising a child with DS; the perceptions of African clan members regarding children with DS; the perceptions of African families in relation to the social work services received whilst raising a child with DS; and their suggestions with regard to how they would like to be assisted by social workers in a culturally appropriate manner. Although the data in this category came from two different sources, it was considered jointly as representing the African clan and was analysed as such. The issues covered in the conversations that took place in the clan interview were similar to those covered in the focus group. The data presented in the following section relates to the African clans' lived experiences as well as their subjective view of the world and reality as informed by their cultural thought and behaviour.

The conversations with social workers took a form of semi-structured individual interviews using an interview guide. The interviews focused on the social workers' experience of working with African clans raising children with DS; their opinion regarding the level of congruence between the services they render and the nature of African clans, their experiences and coping mechanisms when raising children with DS as well as their suggestions with regard to the improvement of social work services to African clans raising children with DS.

➤ Summary information on participants

**Table 2. Information on clans interviewed**

	Gauteng	Limpopo	Mpumalanga	North-West	Sample
<b>Families/clans</b>	7	6	8	6	27
<b>Focus groups</b>	2	1	0	2	5
<b>Social Workers</b>	2	2	3	13	20

A total of twenty seven (27) clan interviews; five (5) focus group discussions with mothers and/or guardians; twenty (20) individual interviews with social workers were conducted across the four provinces of Gauteng, Limpopo, Mpumalanga and North-West province.

Firstly, the seven (7) clans interviewed in Gauteng were made up of a total headcount of thirty-two (32) participants; six (6) clans interviewed in Limpopo province with a total headcount of thirty six (36) participants; eight (8) clans interviewed in Mpumalanga with a total headcount of forty (40) participants; and six (6) clans interviewed in North-West with a total headcount of thirty-five (35) participants. The 27 clan interviews conducted comprised a total headcount of 143 participants. Secondly, the five focus group discussions were conducted in three provinces namely; one focus group of eight (8) members in Limpopo (Tzaneen); two focus groups of twelve (12) and five (5) in the North West province (Potchefstroom and Mafikeng respectively); and another two focus groups of seven (7) and twelve (12) in Gauteng (Coronation/Rahima Moosa and Natalspruit hospitals respectively). A total headcount of forty four (44) participants participated in the five (5) focus group discussions. The focus group had a minimum of five (5) up to a maximum of twelve (12) members as shown above to allow for the effective facilitation of a discussion that would yield required data. Thirdly, a total headcount of twenty (20) social workers were interviewed. This category of participants consisted of social workers assisting African families in health care settings (hospitals) as well as social workers providing welfare services in communities where African clans reside. The total number of social workers interviewed came from the four provinces namely; two social workers interviewed were from Limpopo province; thirteen (13) social workers from the North-West province; two (2) from Gauteng; and

three (3) were from Mpumalanga province. Similar to the sampling techniques used for African clans, the researcher used purposive and snowball sampling procedures to select participants in this second category of participants. As a result of snowballing, the North-West province ended up with more social workers interviewed at two major DSD service points in Potchefstroom and Mafikeng. The management of the service points arranged for the social workers to be available for the interviews, whereas in other provinces, the researcher only interviewed social workers at the hospitals. Most hospitals in the rural provinces only had one social worker. The DSD social workers were not available to be interviewed due to work commitments and lack of willingness from their managers to release them to be interviewed.

➤ **Demographic details of members of the African clans interviewed**

The demographic information of the members of the African clans interviewed in this study is limited to significant aspects shaping the collective identity of the clan in relation to ethnicity, clan identity, religion and type of residential area as crucial demographic aspects yielding significant influence to the findings of the study. For instance, the strength of the clan identity as a bond that connects the clan with its culture and religion has a bearing in determining how each sub-system in the broader clan system processes information about any particular challenge including the birth of a child with DS and how it attempts to deal with it. The following table provides demographic information on the twenty seven (27) African clans interviewed:

**Table 3. Characteristics of clans**

Category	Description	Number of participants
Ethnic group	Ndebele	6
	Pedi	6
	Tswana	8
	Shangaan	1
	Venda	2
	Xhosa	2
	Zulu	2
Clan name	Known	25
	Unknown	2
Location of family	Rural	9
	Urban	18
Religion	Christian	14
	Traditional	8
	Unspecified/no affiliation	5
Social grant status	Recipient	24
	Non-recipient	3
Mother's age at the time of birth of the child with DS	20-35 years	1
	36-39 years	19
	40-50 years	7

The number of clan interviews was determined at a point of saturation after the twenty seventh (27<sup>th</sup>) clan was interviewed. The participants were well spread across the major ethnic groups making up the African population in South Africa. Twenty five (25) out of the twenty seven clans interviewed were aware of their clan name and actively participated in the activities of their clan with a small number of two (2) reporting lack of knowledge and interest in their clan. About eighteen (18) clans came from urban areas with a small number of nine (9) residing in rural areas particularly of Limpopo, Mpumalanga and North-West provinces. In terms of religious affiliations, fourteen (14) clans were Christians although some of them reported vacillating between Christian and African traditional religious practices. This was followed by African traditional religion with eight (8) clans and a small number of five (5) clans reporting that they did not hold any particular religious belief system.

The next set of demographic information relates to the biological parents/primary care-givers or guardians of the child with DS who formed part of the focus group discussions. The demographic information collected relates to the gender, age, religion and level of education. This category of participants was recruited from existing DS support groups and consisted of biological parents (mainly mothers) and, in some instances, primary care-givers other than the mother (mainly grandmothers or aunts). The following table presents the demographic information of parents, primary caregiver or guardians from the forty four (44) participants interviewed in 5 focus groups across the four provinces:

**Table 4. Demographic information of focus groups participants**

<b>Category</b>	<b>Description</b>	<b>Number of participants</b>
Primary care-giver of the child	Biological parent/s	35
	Grandparents or aunts	9
Gender	Male	3
	Female	41
Occupation	Clerical	4
	Domestic/Farm-worker	9
	Unemployed/Pensioner	25
	Professional	6
Marital status	Divorced	4
	Married	17
	Never-married	14
	Separated	6
	Widowed	3
Social grant status	Recipient	44
	Non-recipient	0
Mother's age at the time of birth of the child with DS	20-35 years	8
	36-39 years	7
	40-50 years	29

As would be expected, the majority of participants were female as they generally serve as primary care-givers for children, whether it is their own children or off-springs of their significant others. However, it is interesting to note that a small number of three (3) male participants were involved in supporting their partners. The rest of the forty one (41) participants in the focus group which was taken from the DS support group were females. Although most of the participants, thirty five (35) were biological parents, a significant number of participants, nine (9) who served as guardians for the children with DS were not biological parents but a significant other clan member, usually a 'kokwane' (grandmother) or 'mhaninkulu' or 'mhanitsongo' that is a senior or junior mother to the child with DS or 'sesi': a sister to the child with DS. It is common practice for African clan members to share the responsibility of raising a child particularly with the elder members of the kinship network, be it grandparents or aunts.

On the basis of the twenty seven (27) clan interviews and the five (5) focus group discussions made up of a total of 44 members in headcount, it can be deduced that a total of 71 children with DS were indirectly involved in this study. Given that the focus of the study was not directly on the children with DS but, their clans, no detailed biographical information about the children was collected. However, clan members were asked during the course of the interview about the child and the questions included the place of birth of the child, whether the child received a grant or not and at what stage of the child's age was the grant approved. Most clans and caregivers reported that the child was born in hospital, but a significant number of children were born at home with the assistance of significant other clan members. About sixty eight (68) of the children involved in this study received a disability grant, with only three (3) children without a disability grant. One of the clans did not apply for a grant at all apparently because the parents are public servants and thought they would not qualify and while the other two clans only started the application process recently. One parent only considered applying following the loss of employment and another set of parents only applied after receiving more accurate information about the grant and the criteria for qualifying for it.

Regarding the age of the mother at the time of birth of a child with DS, sixty two (62), 87% of the biological mothers out of the total of seventy one (71) were above the age of 35 which is considered an advanced maternal age (AMA) and only nine (9), 13% of

biological mothers were below AMA. This is consistent with the findings of an earlier study by Lampret and Christianson (2007:516), which found that in South Africa more than 50% of children with DS are born to women of AMA which increases prevalence of DS, making it a common condition in South Africa.

The demographic details presented above regarding the location of the clan in an urban or rural settings; religion; age of the mother at the time of the birth of a child with DS; whether the primary care-giver is the biological mother or a significant-other clan member and marital status of parents bears significance in this study as they influence the clan and parents or guardian's perceptions about their lived experiences of caring for and raising a child with DS while bringing out the resilience of the clan system to sustain itself in different circumstances and contexts. For instance, the data coming out of urban and rural areas show the consistent existence of clan kinship relations/networks and its influence on how the clan system and its members function and perceive their identities. Similarly, the information on religious affiliation confirmed that the African clan derives its knowledge systems from objective and subjective sources including spirituality and intuition/affect regardless of religious affiliation. The age of the mother at the time of the birth of a child with DS confirmed various aspects characterising the African worldview—including the idea that everything is interrelated, interdependent and connected. The fact that when a child with disabilities is born to a younger and less experienced mother, a senior member of the clan (either the biological mother of the young parent, her sister or aunt takes over the role of rearing and primary care-giving to the child with DS and the collective approach to dealing with a matter that could otherwise have been dealt with as a private individual or couple issue in the Eurocentric realm. Finally, the marital status of the parents was significant because it brought out very interesting dynamics including the fact that, parental rights and responsibilities in the customary rules enshrined in the African worldview are exclusively assigned to the maternal family if the mother is not married. This is in direct contrast to the South African legal framework that accords both biological parents (regardless of whether married or not) full parental rights and responsibilities to the child. Additionally, in the African context, marriage through '*lobola*' (bride price) determines the inclusion of the paternal clan and its merger with the maternal clan to become one big clan. Without '*lobola*' and finalization of the marriage, the two clans remain separated and have no ground or point of conjunction.

### 5.2.1 The themes and sub-themes emerging out of the data

The data is discussed according to the identified themes and sub-themes as outlined in the table below:

**Table 5. Summary of themes and sub-themes**

Themes	Sub-themes
1. The nature of the African clan raising children with DS	<p><b>1.1.</b> The clan identity.</p> <p><b>1.2.</b> Clan functioning, structure, culture and tradition.</p>
2. The lived experiences of the African clan with regard to raising a child with DS.	<p><b>2.1.</b> How the clan received the bad news that their child has DS.</p> <p><b>2.2.</b> Coping mechanisms with regard to raising a child with DS.</p>
3. The African clan's intersection with social work while raising the child with DS and their suggestion for improvement of social work services.	<p><b>3.1.</b> Social work services in the hospital and community.</p> <p><b>3.2.</b> Findings related to how the clan experienced social work services in the hospital and the community.</p> <p><b>3.3.</b> The African clans' suggestions regarding how they would like to be assisted by social workers in a culturally congruent manner when raising their children with DS.</p>
4. The social workers' opinions regarding the level of congruence between the social work services rendered to African clans raising children with DS and the needs of these clans, as well as their suggestions for the improvement of social work services to these clans.	<p><b>4.1.</b> Social workers' experiences of working with African clans with regard to services and reception of such services.</p> <p><b>4.2.</b> How social workers manage the lack of fit between social work practice and the contextual realities of the African clans.</p> <p><b>4.3.</b> Social workers' suggestions for improvement of social work services rendered to African clans raising children with DS</p>

## **Theme 1: The nature of the African clan raising children with DS**

The nature of the African clan raising children with DS as a major theme consists of two sub-themes that were explored. These sub-themes were as follows:

The first sub-theme related to the identity and included clan names, clan praises and totems. The second sub-theme related to clan structure, functioning, culture and tradition. The sub-themes have proven to exert considerable influence on how the clan dealt with the experience of raising a child with DS such that without a proper understanding of their influence, one would have not fully understood the clan's dealings with DS.

### **Sub-theme 1.1 Identity of the African clan raising children with DS**

Through the use of the ecosystems lens, the researcher viewed the African clan raising a child with DS as a system made up of various interrelated and interdependent sub-systems as indicated by Ambrosino et al. (2012:50). The clan system is in itself viewed as a sub-system of a broader social system forming part of a bigger cosmic system found in a space made up of various natural, spiritual, social, political and economic systems. All these sub-systems are connected and related according to the African worldview (Ani, 1994:24). For example, the participants interviewed as members of African clans conveyed information that seemed to suggest that their clan identities, including clan kinships and totems, were following a patrilineal kinship system. They all explained their clan names and membership to the clan through a paternal line. None of the participants traced their clan or kinship identity through the maternal line, unless in exceptional cases such as when the parents were not married. This is consistent with Meiser et al. (2008:439) and Penn et al. (2010:12)'s assertion that African families follow a patrilineal kinship system. However, it was found not to be entirely true but partially correct. Relating to the research data, the existence of patrilineal kinship lineage amongst African clans raising children with DS was reflected by the participants' consistent reference to the paternal side of the clan as defining clan identity. For instance, the data confirmed that married couples would always derive their clan identity from the husband's paternal clan side if the husband's mother was

married and, if the husband's mother was never married, the husband will then adopt the maternal grandfather's surname. Conversely, a single-parent household would derive its identity from the woman's paternal clan side and, if the woman's parents were never married, she would derive her household identity from her mother's paternal side of the clan (use maternal grandfather's surname). One unmarried mother had this to say about what she considered household and clan identity:

*“sefane se rekwa ka dikgomo....nna ke mokgakga le banaka ke bakgakga....ntle le ge ditswile shakeng.” (a surname or family identity is bought with cattle...I remain 'mokgakga' (clan name)...until such time that I am married (bride price paid usually using cattle).*

However, contrary to the assertion made by Meiser et al. (2008:439) that, African clan follows a patrilineal kinship, the findings of this study reveal evidence of both patrilineal and matrilineal kinship amongst Africans. Although clan identity is derived from the paternal side, the maternal side of the clan seems to exert an equally important influence in what seemed to be complementarity rather than binary oppositions. It appears that kinship arrangements within the traditional African clan system cannot be fully understood without the maternal side. The maternal side is still viewed as part of the clan system. Therefore, the two are seen as mutually inclusive to the effect that you cannot fully comprehend one without the other. One of the participants had this to say about the nature of kinship networks in her clan:

*“Although our identity comes from our fathers' side of the clan, our clan comprises both our fathers' and mothers' clans...”*

The researcher deduced that within the traditional African family context, patrilinealogy and matrilinealogy are like two sides of the same coin. Using the ecosystems theory, one could view them as sub-systems within a unified and integrated clan system. The participants reported that their maternal side of the family forms part of what they considered their clan and emphasized that marriage is viewed as an extension of a clan where the bride's clan joins in with the groom's clan to become one big clan system. As eloquently put by one of the participants from the clan interviews:

*“... in our culture marriage is an extension of a clan through a merger with another clan to become one big clan system. Without marriage, even if people live together and have children they are not considered part of one clan system and their different clans are not joined to form one clan, but once lobola is paid, the two clans become one and we cannot consider one side without the other... the children will have brothers and sisters from both sides of the father and mother. When ceremonies and rituals are conducted, both sides of the clans must be represented”*

The data shows that siblings linked to one mother together with their offspring form a critical subsystem within the broader clan system and relations. In the Shangaan ethnic group, there is distinction between different sibling sub-systems as comprising ‘xinwana tatana’ (siblings traced from paternal side) and ‘xinwana manana’ (siblings traced from the maternal side). This means that children of a father and his male siblings become siblings (brothers and sisters) and similarly children of female siblings become siblings (brothers and sisters). This has been confirmed by literature on traditional African family systems reaffirming that in some African tribes traditional leadership and spiritual inheritance follow a matrilineal lineage (Nyathi, 2005:26). This means that siblings who trace their sibling relationship through their being born to mothers who are siblings are viewed as heirs to the throne as they share royal blood and can succeed or inherit traditional leadership.

A further example of matrilineal influence on kinship revealed through this study is the practice of witchcraft and traditional healing, which is believed to be transmitted and inherited through the maternal line. Its inheritance is said to be linked to breastfeeding such that children sharing the same breast are all guaranteed such inheritance from one generation of siblings down to grandchildren along a maternal line. Consequently, when an allegation of witchcraft is made against one member of the clan, all siblings and progeny from a maternal line are implicated, the participants revealed. One member of the clan had this to say about inheritance:

*“kuna vuxaka bya xinwana manana ni vuxaka bya xinwana tatana... iswa ndyangu wunwe kambe swihambanile. Vamakwavo va xinwana tatana iva makwavo kambe avaloyi swinwe... vamakwavo wa xinwanamanana vamame rinwe, valoya swinwe. Aswendli unwani ava noyi unwana avahava vuloyi hikuva vamame vele rinwe, xiritano*

*xintu xa hina*” (There is both matrilineal and patrilineal kinship relations... in one clan, but they differ. Paternal siblings are siblings, but they cannot share witchcraft traits... but maternal siblings fed and shared one breast, share witchcraft traits. It is impossible for one to be a witch while the other is not because they were fed these traits through the breast. That’s what our customs says).

The participants reported that the nature of clan relations along the maternal line carries the same weight and meaning as those existing amongst siblings related along paternal lines. At times the maternal line is much stronger than the paternal one. For example, the participants had these to say:

*“... the children of my husband’s brothers are my children’s siblings...but my sister’s children are also my children’s siblings.. they are all brothers and sisters and part of the clan...”*

*“I live with my sister and her children... we are all part of the clan.”*

*“Mpho (child with DS, pseudo name used to protect child’s identity) is not my biological child, but my sister’s... she is my child, she lives with me and my other children, we are part of one clan.”*

*“Although our family extends from the father to the mother’s side, it is easier to live with my sister and her children than my husband’s brothers and their children...the bond is stronger on the maternal than the paternal side.”*

Although some clans did not mention the relationship between the paternal and maternal side of the kinship as forming part of their kinship system during the course of the interview, their biographical details attested to it. In one household they had clan members related and linked to the clan through the paternal line and others linked to the clan through a maternal lineage. All these people were regarded as part of a clan. This then reflects a lived reality or their existential condition, according to Sithole (2016b:182) where he says that the existential conditions of Africans should be engaged from the ‘*ontological zero point*’—which means that they should be understood from their lived experiences and their form of living that is reduced to non-

existence (lack of ontological density), but possessing the ability to emerge. For instance, in theory, there is no matrilineal kinship amongst Africans as it is in western families, but a closer analysis of the existential conditions or lived experiences of African clans raising children with DS reveals otherwise: indeed the matrilineal kinship does exist and exert strong influence within the African clan context. Essentially, the above finding on the co-existence of patrilineal and matrilineal kinship reaffirms the collectivist and integrated cosmos within the African worldview and philosophy where everything is connected and interlinked, but such reality is denied by mainstream scholarship. At the same time it represents one of the inherent strengths in the African clan system as explained by Cummins et al. (2006:42) and Zastrow (2004:60).

A similar argument is made within the Afrocentric circles about the connection and complementarity between the sexes or genders. A male is not seen in isolation to a woman, but connected and thus making it impossible for one to have more power and oppress the other (Ani, 1994:95). Actually, Ani (1994:95) argues that men, no matter how much power they might have, may never live and sustain themselves entirely without women, and women too cannot be without men. The findings are in keeping with the seminal theorization of the African cultural thought and worldview by Ani (1994:95) when she proclaimed that contrary to the dichotomous and splitting European view, the African worldview with its cosmic view of reality is unifying and integrative, seeing everything as connected. She further explains this in terms of a universal principle of complementarity or twinness which creates wholeness and establishes equilibrium, cooperation, balance and harmony as illuminated by the ecosystems theory. This is indeed an opportunity and strength inherent in the African philosophy and worldview which may otherwise be viewed as a challenge in a Eurocentric context (Meiser et al., 2008:441).

It is therefore understandable that Eurocentric scholars such as Meiser et al. (2008:441) view certain elements of the African clan system in isolation and opposition to other elements of the system. This is indeed consistent with the splitting view of the European cultural thought and behavior, but alien to the unifying African cultural essence and worldview. The social constructionism as a theory that views knowledge as being constructed rather than discovered provides a useful tool of analysis in trying to understand how the African worldview and its underlying philosophy as socially

constructed. Thus, the African worldview as a social construct is also constantly and continuously subjected to various forces that influence and shape it in some ways. The various forces that influence it are illuminated through the ecosystems theory.

Similar to western societies, marriage as a socially constructed institution is an important marker and initiator of the institution of family and its expansion (Russell, 2003b:12; Siqwana-Ndulo, 1998:408). The data show that without marriage, the identity of an unmarried young woman with children and by implication that of her children would not change in the context of traditional African families. Below are some of the responses attesting to this:

*“...in our culture marriage is an extension of a clan through a fusion with another clan to become one big clan. Without marriage, even if people live together and have children they are not considered a clan and their clans are not joined to form one clan, but once lobola is paid, the two clans become one and we cannot consider one side without the other.”*

*“Without lobola... the biological father cannot be recognized... the ancestors of both families are not united and therefore the father or his family, have no say in the affairs of the child or the child's mother...”*

*“I am not married... I use my father's surname and my children too use my father's surname. The children are part of my family and they belong to my parents and the elders.”*

The findings show that this practice is not limited to clan identity or clan, but includes unification of ancestors and spirituality between the clans. It also goes a long way as a significant condition for any kind of interaction and relationship, including the allocation of power and authority over the affairs of the individuals concerned in the African clan context. For instance, when a child is born with DS to an unmarried mother, her own clan reserves authority and control over what is done with the child's condition without any regard for the biological father and his clan. This extends to naming practices of the clan, traditional practices, cultural and spiritual rituals, and any other action that may be required in relation to the child's medical condition. All these remain an

exclusive domain of the maternal clan's control through her father as head because the clans are not yet connected spiritually through a marriage ritual that brings the two clans together as seen with the verbatim accounts cited above.

The participants went on to stress the importance of knowing and understanding one's own clan, its totem and being able to recite praises of one's own clan. A common feature amongst the tribes and ethnicities in this study is the fact that their totems are animals. The participants appear to hold the clan name, its totem and clan praises in high regard. This is confirmed by at least sixty eight (68) of the seventy one (71) clans from the focus group and clan interviewees who highlighted the importance of knowing one's own clan name and totem as well as the ability to recite praises of one's clan. As eloquently put by one participant:

*“Go bohlokwa gore re tsebe le go kwishisha gore rena Bahwaduba re dikgomo...ka maoto eya raga ka dinaka eya hlaba” (it is crucial that we know and understand who we are as a clan. Our clan name is ‘Bahwaduba’ and our totem is cattle, it butts or gores with its horns, and kicks with its legs)*

The above member of a clan highlighted the significance of the symbolism embedded in their clan totem. They reported that its significance is in the enactment of the characteristics and deeds associated with cattle in the African context, which includes its high value in society, its usefulness in feeding and serving as an instrument of production of valuable products for the family including ploughing in the traditional African agrarian society. Thus, they emphasised that the ‘Bahwaduba’ or ‘Kgomo’ (the cattles) as they are commonly known are expected to resemble the same characteristics in their behavior patterns and conduct.

An unmarried, but cohabiting Motswana woman with a partner and children gave her paternal family's clan name when describing her family identity as follows:

*‘Ka moano re bokgabo- bo Kgabo Mokgatla e ja borekhu’ (we are monkeys feeding on tree gum).*

The unmarried, but cohabiting Motswana lady knew the clan name and totem, but she could not recite praises of the clan. However, she knew that this was all important for her to know her family identity.

Another Shangaan family known as Mahlabane is part of the Mangwane clan. The Mangwanes originate from Swaziland also known as 'KaNgwane'. This particular Shangaan family knew clearly what its clan name means including its praises and totems. The family reported that its totem 'Mangwa' refers to a Zebra. This translates into Ngwane in Swati, hence formerly known as 'KaNgwane'. The clan includes surnames such as Mkhwanazi, Hlomela, Tshabangu and they always conclude their clan praises as follows:

*"...Ngwane ya malandzela, Mswati, Ngwane le nhle" (a Zebra, a descendent of Malandzela which is their great ancestor from whom they descended, a Swati, a beautiful zebra).*

When asked to explain further, the father in the family who is considered head of the household said that a Zebra is clever, clean and beautiful, so are the Mangwanes as per their clan praises. The expectation is that the Mangwanes as Zebras should follow what the zebras are doing. An interesting observation in this regard was the fact that males, particularly older men in the clan were more knowledgeable about the clan identity than their female counterparts. They were able to name the clan and totems as well as recite the praises. However, females were particularly good at reciting their own maiden family's clan praises.

Another Shangaan family interviewed was the Makhubele family and their clan name is 'vaGwena' (plural) and 'mGwena' (singular) from 'Ngwenya' which is a crocodile. Their totem is a crocodile. Like crocodiles, the family sees itself as strong and dangerous. The family members regard themselves as fighters. They reported:

*"We Makhubeles are crocodiles...the greatest, most brave, dangerous and most feared creatures under the water...we are not cowards... we are not fearful." (then the aunt recited the clan praises...).*

Again, only the elder male of the family was able to give most of the information whilst the women and children seemed to be less informed. Except for the aunt who was able to recite the clan praises. On follow-up the family emphasized that the clan name and its associated totem signify not only an identity, but their characteristic behavior pattern and habits of the people of the clan as well as spiritual thoughts. They emphasized that it is instructive on them and raises certain expectations of specific social behaviors. They stressed that it is also spiritual as the whole clan look up to the totem to lead and guide them through the life journey.

*“We communicate with the crocodile... it is part of our spiritual ritual. It connects us to one another”.*

It appears that the clan name and the totem as well as associated clan praises become the glue that connects people to their kinship systems, to their land and the cosmos. For instance, some of the African clans have a lion as their totem and from this totem they derive the clan's expectations of its people to be strong and heroic at all times. They reported that this covers everyone including children born within the clan. Asked about the child born with DS, the families reported that they expect the child to fit in with the characteristics of the clan, regardless of the condition characterized by mental and physical malformations and disabilities. This demonstrates the important role played by spirituality within the African clan and how this strong believe enables them to deal with challenges that come its way.

Although some participants could not recite their clan's praises, the majority of them knew how to recite and explain their family clan names, poems and totems. Some knew their clan name, but not the totem, while others knew the totem, but not the clan name. Those that could not recite blamed it on the elders and the head of the household/the husband or children's father who did not make efforts to teach the wife.

*“...bagolo baile le tsona badimong..., ntate jaaka tlhogo ke ene fela a itseng mme ga a re rute...” (Elders left with them to the grave and the father as the head of the household knows, but he does not teach us).*

They all viewed the clan name, poem and totem as important and emphasized that it is crucial for their children and grandchildren to learn them so that they could be passed on from one generation to another.

*“kutlula ka mhala ku letela ngwana wa lendzeni... hi fanele ku dyondyisa vana kuri va kota ku dyondyisa vana va vona na switukulwana, ndavuko wa hina wunga lahleki.”*  
*(A springbok’s sprint is a training opportunity for the baby inside her womb, we should teach our children about their family identities so that they can teach their own and grandchildren, it is important for the preservation of our culture).*

The above statements present yet another important element of clan identity which relates to continuity and transmission of values from one generation to another. The clan name, praises and totems are reported to serve as important mediums for the transmission of important messages of collective learning within the clan that gets transmitted across generations. It has been argued that due to the fact that indigenous cultural orientations are not reflected in the knowledge base of social work, a need exists for social workers to urgently seek a deeper analysis of the implications of culture for humans and how they view the world (Marais & Marias, 2007:813; Laungani, 2004:35). The data about clan identity, including the use of totems and praises, seems to carry so much meaning for the African clan raising a child with DS that without a deeper understanding and appreciation of these factors, social workers assisting these clans are likely to miss out on the influence of these aspects on how the clan views their experience of raising a child with DS.

Siqwana-Ndulo (1998:410) avers that it is important to recognize the fact that the African clan or household organization is part of a social system with a cultural heritage based on a value system quite distinct from the western one. She further argues that the African clan system should be analysed from an objective account of the influence of African cultural beliefs and social behavior as they are adapted to various historical developments and periods in their history instead of imposing Eurocentric views (Siqwana-Ndulo, 1998:410). Therefore, a proper understanding of the identity of the African clan raising children with DS is very vital when considering psychosocial assistance for the clan. In the context of the African clan system, the nature of the identity of the African clan comprises the clan name, its totems and clan praises. These

are not only descriptive labels, but represent very meaningful artefacts that are sacrosanct and symbolic in character. These artefacts give the African clan its identity and define how the clan sees the world and its different experiences, including the birth and raising of a child with DS. The data show how the different clans interviewed reacted to the experience of raising a child with DS in line with their clan identity. For example, the clans whose totem is a crocodile expected their children to be strong and dangerous as young crocodiles. They did not expect one of their own to be weak and slow as found in DS. Furthermore, the role of marriage in the life of the clan has significance as it determines the allocation of parental rights and responsibilities. However, it must be noted that despite its resilience, the African cultural essence is not always intact due to the devastating effects of colonialization. Therefore, in some instances, African clans raising children with DS were found to be unfamiliar with their own cultural orientation. The next sub-theme addresses the functioning of the clan, structure, culture and tradition.

### **Sub-theme 1.2      Clan functioning, structure, culture and tradition**

Cognizant of the limitations imposed by the use of a foreign language (English) in the presentation and analysis of data collected from African families about their lived experiences understood in African terms and aware of the incomplete and reductionist use of the English language in contrast to the more inclusive, symbolic and integrative African languages, the researcher tried to clarify and amplify the different meanings attached to certain words in English and African languages. For instance, in order to uncover the understanding and meaning attached to the word 'family' by African families and to establish if the word bears similar meaning to the English word, participants were asked to reflect on what they considered to be family and what word do they use to explain it in their vernacular. The researcher elected to use the word clan to refer to the African traditional kinship arrangements and use family for the western meaning of the word family. The findings reveal an apparent absence of vernacular terminology that explains 'family' in a manner that compares accurately with the conventional English concept of family. An exploration of all the African languages included in this study and spoken in South Africa shows that none of them have a term with similar meaning as that of family in the conventional western sense. For instance in Xitsonga, 'Ndangu', or 'Lapa' in Sepedi or 'Mdeni' in Zulu refers to a clan with its

collection of households linked to the clan and other alternative terms such as 'maxaka' in Xitsonga refers to blood relatives. These were the words used by participants to refer to or when speaking about their understanding of what a family is in their view. When for instance, a Mopedi person talks about 'lapa la ga Lekganyane' they are not referring to a single household, but to a collection of households in that clan. There was consensus amongst the participant members of African clans that what they consider as 'lelapa' is in fact a collection or network of kinship that may come from a single or multiple households ('malapa' Sepedi/Mindyang-u-Xitsonga). These cannot be referred to as extended families, but a clan. As confirmed by the following responses:

*"Our culture is different from the western one, although we understand what a family is, this is derived from the English culture. Our African culture embraces everyone in the clan including grandparents, children, grandchildren as well as the in-laws as one 'lapa'. All are part of one 'lapa'. But in the western culture, family means the husband, wife and children. We do not have a word for that, but we use different words that cover everyone related by blood."*

*"We have different words for family in our culture, but it is not the same as the English word even though we usually borrow the English word, but we refer to something different."*

*"We use the word 'ndangu' in Xitsonga when we talk about family to refer to everyone related by blood from the father and mother's side. We are a family."*

*"In Sepedi lapa refers to the whole clan including other clans related to it through marriage."*

This is consistent with the definition of African traditional family by Siqwana-Ndulu (1998:415). In essence, one may safely argue that the concept and phenomenon 'family' as espoused in the conventional western lexicon does not exist in the African existential realm. The lack of a word equivalent to the English word may be interpreted to imply that such a concept or phenomenon does not mirror the existential reality of Africans. This is further illuminated by the use of different words/terms with different meaning though related to family such as home; relatives; kinship and household do

exist. Therefore, the use of the word traditional African family is also misleading as there is no such thing as traditional African family in the African existential realm, but a mere clan system.

As indicated earlier in the literature chapter, family in the western society refers to the conjugal pair who maintains a household with their offspring or adopted children while anyone else outside of this circle is 'extended family' (Russell, 2003b:162; Siqwana-Ndulo, 1998:408). The participants were asked whether they have a word for extended family in their languages. They responded as follows:

*"We don't have such in Sepedi, once you are related by blood; you are part of the 'lapa' (clan)."*

*"Xitsonga does not have such a word, we only have 'ndangu' and everyone forming part of the clan either by birth or marriage is part of it."*

*"In Setswana, we do not have such a word, you are either a member of the family or you are not, but everyone in the family including grandparents, siblings, grandchildren are part of the family."*

*"In Ndebele, we don't have such a word, what white people refer to as extended family, we see as part of the family."*

Contrary to the western nuclear family structure, the African clans interviewed were made up of an extended network of members related by blood, found either in one or more households defined in terms of patrilineal and matrilineal kinship systems. For the lack of a suitable word in English, one would refer to them as 'extended families' when considering family structure in the western sense. In terms of the African clans interviewed in this study, some of them were made up of three to five households that viewed themselves as one clan.

The literature has according to Siqwana-Ndulo (1998:411) shown that, Africans are more likely to reside in extended family households than whites. Furthermore, the writers who view African family as pathological see it as a "cultural deviant" in the

context of western society. Russell (2003a:7) researched African family structure and found that black people in urban and rural areas have a distinctive system of household formation, quite unlike that operating among whites. The above findings were also confirmed by the 2002 census. After a comparison of the frequency distribution of households of various sizes for whites and African in both rural and urban areas, Russell (2003b:153) concluded that African families in urban areas were not becoming smaller despite the pressure to individuation, competition and consumption. There was no eminent convergence of black and white urban family distributions. Meaning that, despite the pressure and fierce assault imposed by modernization on the African family system in South Africa, it has remained resilient and retained its unique character distinct from the western nuclear family structure.

The following statements from the data attest to the validity of the above assertions:

*“We have our own household, but this household is not a family on its own, it is an extension of a family. When our children branch into their own houses, they too will be an extension of the family, we are one family.”*

*“The elders are the traditional owners of the family, whenever there is a big decision to be made, we consult them because they are the owners, we are just branches they are the trunk of the tree, a branch cannot be a tree on its own.”*

*“When we have family meetings, we get together with everyone, the elders, relatives, grandchildren and we sit as one family to discuss family issues.”*

The data show that the notion of the ‘family’ as a borrowed concept commonly used by the Africans does not mean the same thing as the conventional western use of the word. It does not centre on a conjugal pair and not limited to a household. It was however linked to both patrilineal and matrilineal kinship system and made up of numerous households. The participants were asked to share some of the different roles that different members of the clan in different positions play.

*“Different members have different roles, we have grandfathers and grandmothers who play a unique role and aunts also have a special role in our families especially when there are marriage ceremonies.”*

*“Grandparents serve as advisors and are seen as think tanks for the family. Younger couples and family members usually turn to them for advice in times of difficulty.”*

*“Grandfathers are also perceived as anchors for the male members, while grandmothers anchor the females and serve as midwives when children are born at home.”*

*“Uncles like aunts also play a significant role in marriage negotiations and representing the matrilineal side of the kinship when it comes to the bride and her children.”*

*“Grandparents are custodians of wisdom and information about the identity, history and functioning of the family and life in general. They are also problem solvers and valued social support system for the younger members of the family. They will always be the ones to be consulted when there are problems in the family and their intervention is expected to be widely accepted and respected by everyone in the family and any defiance is viewed as deviant and punishable by ancestors.”*

*“Grandparents or elders cannot be questioned or interrogated by anyone in the family.”*

Bakgekolo' (maternal grandparents) are also instrumental in leading households belonging to the same clan in observing family rituals and practices associated with child bearing. One ritual and practice prevalent in all the tribes is known as 'go thusa ngwana' in Sepedi. One participant from the Bapedi ethnic group stressed that:

*“bakgekolo ba thusa ngwana ka morago ga beke ba be ba mo ntšhe ka ntlong...go bohlokwa... ka gore ge ba sa dira bjalo...ngwana a ka tla a hlagelwa ke bothata.”*  
*(female elders perform rituals to strengthen the baby a week after birth and also lead a ceremony to expose the child to the environment outside the house in which he/she was born... this is very crucial...because if they do not do that... the child may have problems).*

The above statement shows the important position of female elders in the family. As asserted by Kasanga and Lwanga-Lumu (2007:66), the role of elders has been described in relation to teaching and bringing up children and guiding them through illness. A similar sentiment is echoed by Barratt and Penn (2009:195) who argue that grandparents serve an important role as gatekeepers of knowledge about illness and treatment in African families.

The issue of elders performing certain rituals following the birth of a child seems to be a standard cultural practice across different African ethnicities although it is applied differently depending on the family's belief system. Some participants who are inclined to Christianity reported that they deal with it through a prayer service, while traditional believers pointed to traditional rituals and ceremonies as discussed above. Some amongst those that belong to the so called charismatic churches dismissed speculations that if the rituals are not performed the child may experience some problems as unfounded and flawed. They instead presented faith as the ultimate determinant of one's fate rather than rituals and traditional practices as indicated in the following response:

*"It is all about faith... everything else is superstition. In our family we do not perform any ritual when a child is born. We just pray for the child and all of our children were brought up that way."*

The grandparents are followed by the malomes (uncles, a brother to one's mother) and 'hahani' in Xitsonga/ 'rakgadi' in Sepedi and Setswana (aunts, a sister to one's father) in the hierarchy of roles and status within the traditional African family institution according to the data. In English, the word uncle refers generally to a male sibling of any of your parents be it a male sibling of your father or mother and the same applies to an aunt which should be a female sibling of any of your parents. Conversely, the findings reveal that within African traditional families across all the seven different ethnic groups included in the study, a 'malome' (uncle) refers only to a male sibling of one's mother and hahani/rakgadi (aunt) refers exclusively to a female sibling of one's father. The participants reported that all male siblings to one's father are regarded as fathers. They are either referred to as 'papakhulu' in Xitsonga/ 'ramogolo' in Sepedi,

'ntatemogolo' in Setswana, 'babamkhulu' in IsiZulu which translates to a senior father in English and 'papatsongo' in Tsonga for junior father in English depending on their seniority to one's father. The same applies to the female siblings of one's mother, they are equally referred to as mothers, either as 'mhaninkulu'/'mamogolo'/mamkhulu for senior mothers or 'mhanitsongo'/'mmangwane'/'mamcane' for junior mothers.

The 'malomes' and 'hahanis' seem to play a very important role in marriage negotiations and ceremonies as well as other important life events such as birth and burial ceremonies and rituals, as confirmed by the following response:

*"They are entrusted with leading the negotiations and representing each side of the family, the 'malome' representing the bride's family while the 'hahani' or 'rakgadi' represents the groom's family."*

However, the participants highlighted that only the 'hahani' is allowed to recite the clan praises including calling the clan's totem as a way of introducing an individual member of a family in different ceremonies such as births, weddings and burials.

*"Rakgadi ke yena konokono ya direto, re lebeletše yena ka moka ga rena." (the aunt is a paragon of clan praises, we all depend on her.)*

This is again a clear confirmation of the existence of both matrilineal and patrilineal kinship system in traditional African families as the 'hahani' represents the paternal family and the 'malome' represents the maternal family.

The participants reported that a male partner within a conjugal pair in an African family assumes the role of head of household.

*"A man is always the head of the household in our culture, but he must always work with his wife and elders... Elders are the traditional owners of the household."*

The role may extend to his siblings and even his father and male children in his absence, but it is always complimented and shared with the wife. They reported that major family decisions are taken in consultation with the broader network of elders in

the family during family meetings which are attended by elders as well as couples, uncles and aunts. This is confirmed by what the participants had to say:

*“When there is a problem or festivities, the family comes together, the elders, uncles and aunts are informed and they come together to discuss.”*

*“When a child is born elders must be informed and everyone else including the uncles, aunts, etc...”*

*“As soon as we realised that the child was not well, we informed the grandparents and then the uncles and the aunts. Each one of them gave advices with the elders calling for a traditional ceremony to be conducted.”*

*“The aunts suggested that we consult a sangoma to hear what the problem is with the child.”*

*“The grandparents went and consulted a sangoma and then brought some muti for us to use in the house for the child with DS”.*

The participants also reported that child rearing is a collective responsibility for everyone within the family and extends to the community. There was consensus across the seven ethnic groups regarding this matter. Although some acknowledged that this is changing due to the influence of western culture and the law that gives biological parents and the children the primary responsibility and rights, as put below by some of the participants:

*“The child belongs to the whole kinship, not just the couple. All major decisions about children are taken by the broader family including naming, initiation, discipline, marriage etc. The family as a unit collectively share rights and responsibilities for caring and raising the child.”*

*“The whole family works together to raise children, anyone can discipline the child, give them some chores to do or send them somewhere, but things are changing. These*

*days the children have rights and you cannot discipline them and some parents are too protective.”*

*“I live with my sister’s child and I treat her as one of my own to show that children belong to the clan and not just their biological parents.”*

The above verbatim accounts indicate that the kinship system is made up of different people in different positions and status in the collective life of the African family. The kinship system determined and guided the manner in which these positions and status interacted with each other in line with collectively determined responsibilities, obligations and reciprocity. For instance, some single parent households (female headed) included their parents (children’s maternal grandparents), brothers and sisters as part of their family, whereas conjugal pairs included both the wife and husband’s parents (grandparents to their children), sisters (aunts) and brothers (uncles) as well as their children (cousins). These wider circles of people referred to as ‘extended family’ in the conventional sense of the family are not only viewed as family but in some instances are found to share a household. In cases where members of the family did not share a household, they asserted that their different households are an extension of one family rather than separate families. The paternal parents or grandparents are viewed as the traditional owners of the households or the broader family. For the younger parents with a child with DS, either their biological parents or aunts (grandparents to the child with DS) take over the care of a child with DS without any formal appointment as foster parents or legal guardians as they consider themselves family.

The participants reported that they have particular naming practices in their family that are ethnic specific. For instances the participants shared the following about their naming practices:

*“In our Sepedi culture, children share the names of their paternal and maternal grandparents starting from the paternal to the maternal side.”*

*“As the Shangaan tribe, the responsibility of naming is given to the paternal family including all parties’ involved (conjugal couple, parents and aunts).”*

Additionally, some participants reported that sometimes names are derived from personal and family circumstances and eventualities.

*“If a child is born during a mourning period following the death of a significant other, they are given names such as ‘Mahloko’ (tribulations/sorrow).”*

*“We are Christians; we give our children either a Christian and African name or sometimes a combination of both, sometimes a Christian name without consideration to traditional naming practices.”*

*“Often the child follows in deeds, talents and habits to that of the owner of the name.”*

*“Lebitso ke seromo” (a name is instructive on its bearer).*

*“When a child is named after an elder, we will also treat the child in ways that are similar to the owner of the name, for example, when a child is given a grandparent’s name, the clan members show the child the same respect as they would show towards the grandparent.”*

The clans reported that children with DS are also given the clan names regardless of their condition and would receive the same treatment as would a normal child. As one member of a clan mentioned:

*“Our daughter is given our grandparent’s name, she cried for the name and we gave it as we believe she inherited her spirit. We believe that the condition was a way of the ancestors communicating with us. We are taking good care of her and believe there is more to come from this child.”*

Some of the clans interviewed had given the child with DS a neutral new name. This may be attributed to modernization which leads to the erosion of traditional African practices. Similar findings were revealed by Chauke (2015:305) when he advanced that the Shangaan (Vatsonga) as a people have a tendency to enshrine any event that is considered memorable in a name and therefore names are chosen for their

beneficial influence on the life and character of the bearer. Some clans reported that giving a child a name from the clan, be it from grandparents or aunts, is a form of succession and transmission of personal and spiritual embodiments from one generation to another.

Similar to the nature of the identity of the African clan, the above findings on the African clan's functioning, structure, culture and tradition have serious implications for how professionals such as social workers engage with the African clan system. The social work profession cannot follow the same process used with families from a completely different cultural background when dealing with Africans on the basis of the unique dimensions of the African clan revealed in this study. The nature of clan relations within the African clan system calls for a focus on the clan system as a whole in order to harness the different roles and role-players involved. Any intervention that does not tap into these important role players and their roles has a risk of bringing imposed solutions that cannot be sustained within the clan system or may instigate further tensions within the clan system.

As advanced by Ware, Idoko, Kaaya, Biraro, Wyatt and Agbaji (2009:41), there are differences regarding autonomy, protection of confidentiality between European and African families on the basis that, contrary to Europeans, Africans tend to pursue collective decision-making and a social responsibility for health. They then on the basis of this assertion, call for a model of social decision making and social responsibility as the most suitable and more compatible technique when working with Africans. Similar sentiments were shared by Port, Arnold, Kerr, Gravish and Winship (2008:135). The implications are that when dealing with Africans, social workers need to either develop special approaches and techniques or adapt the existing ones to focus more on the clan in the helping process and adopt a collective rather than an individual approach (Ware et al., 2009:41; Port et al., 2008:136). The researcher maintains that despite adding new indigenous theories, existing theories such as the ecosystems theory and strengths perspective can be adapted and used effectively to meet the needs of African clans. However, such theories should not be used the same way they are used in the Western context, but should be tailored to effectively focus on the clan as a system and tap on its strengths and opportunities. This would be effectively achieved through grounding them within the African existential philosophy and the African worldview so

as to find expression in the actual lived experiences of African clans. This will ensure that social work intervention with the African clan system as a client would become more responsive and congruent with the African culture and worldview.

## **Theme 2: The lived experiences of the African clan with regard to raising a child with DS.**

This section known as lived experiences of the African clan comprises a sub-section on how the clans received the bad news about the child's diagnosis of DS as well as a sub-section on their coping mechanisms thereafter. The section reflects on the experiences as lived and accounted by the African clans themselves.

### **Sub-theme 2.1: How the clan received the bad news that their child has DS**

Out of the twenty seven clans interviewed, twenty three (23) reported that their child with DS was born in hospital with a few of them, four (4) (all of which came from the rural areas) reporting that their child with DS was born at home. A major determinant of where the child was born seems to have depended largely on socio-economic conditions of the family seeing that all urban based families (18) had their children born in hospital whilst four (4) out of nine (9) rural families had their children born at home. Given the historically racialised and geographic disparities in the distribution of health facilities and resources, the findings depict a skewed picture with rural areas poorly resourced while urban areas have most of the much needed health facilities. Those found in deep rural areas, inhabited largely by Africans and characterised by lack of health facilities, were found to have more incidences of child births at home under the guidance of elders as midwives, whilst those found in more affluent urban centres historically inhabited largely by whites with ample health facilities, delivered their children in hospitals.

The same conditions also influenced when and how the diagnosis of DS was made and communicated to the parents. The rural diagnosis were made long after birth and they were mainly clinical diagnosis (based on characteristic features present on the child identified on examination by a medical doctor) without confirmatory diagnostic tests while their urban counterparts had their children diagnosed immediately after birth

or within a short period following birth. Out of the eighteen (18) urban based clans, ten (10) children were diagnosed through a combination of both clinical and confirmatory diagnostic tests. Some of them were told immediately after birth that the child had a problem and post-natal diagnostic tests had to be conducted to ascertain the diagnosis, while some were identified prenatally due to them being high risk due to the mother being of advanced maternal age.

Some of the mothers based in Gauteng received genetic counselling following a positive diagnosis of DS on their child. None of the mothers coming from the three rural provinces of Limpopo, Mpumalanga, North-West received pre-natal screening and diagnostic tests despite some being of a high risk associated with advanced maternal age (AMA). All of the nine (9) children born in rural areas were diagnosed clinically and never took any post-natal testing for DS, while some never received a diagnosis, but realised after delayed milestones that there was something wrong with their child and started investigating until they established through a clinical diagnosis that the child had DS. This implies that many children in rural areas are likely to go undiagnosed owing to the lack of public awareness about DS as a condition. None of the biological parents in rural areas received genetic counselling. However, some of them were given some form of counselling by either the nurse or doctor and later referred to a social worker for further counselling and on-going support. The rural-based support groups are facilitated by the mothers and primary care-givers themselves, whereas those found in urban areas are facilitated by the DSA in collaboration with allied health professionals at various hospitals.

All the participants across the clan and focus group interviews confirmed that there is no name for DS in any of the seven African ethnic languages involved in this study. About thirteen (13) of the clans interviewed (includes all 9 rural-based clans) had never heard about DS until it occurred to them, whilst fourteen (14) urban-based clans knew about it, but never thought it would one day happen to their children. The mothers called it DS, but also referred to the child as '*ngwana wa segwele*' meaning a child with disabilities. Both the mothers and clans did not have any problem or sensitivity about using the word '*segwele*' (*disabled*). The mothers and clans would refer to their children as '*bana ba digwele*' (children with disabilities) without any reservation. The participants reported that the same names were used by doctors and nurses when

talking about the child or children with DS. They referred to them as '*bana ba ba bokowa*', some called them '*bana ba ba sa itekanelang*' meaning children with disabilities and used this interchangeably with DS almost as if they mean the same thing whereas the explanation referred generally to all forms of disabilities. This pointed to a lack of a specific vernacular term for DS. This is also consistent with the African worldview's unifying and integrative approach to reality contrary to splitting and separating approach used in the European approach to reality and cultural thought. To the Africans, any form of disability is generalized as disability with little interest in finer details that separate and distinguish it from other forms of disability. This was confirmed when participants were asked whether there are any specific names distinguishing different types of disabilities, they said:

*"We can only distinguish between different categories of disabilities such as blindness, deafness, dumbness, mental disability etc...."*

*"As black people, we have a different way of looking at these things, we know that doctors can explain it in terms of their scientific understanding of the cause of the condition which we appreciate, but we also have our own understanding which informs how we deal with the condition."*

*"A child with any kind of disability is a gift from God, the doctors can explain it in a particular way and even give it a name, but their understanding is limited. There are other forces at play which they do not understand, so we do not need to throw anything away. All these things must be pooled together."*

This way of looking at disability seems to point to the fact that the causal factors are not central to their view of disability. There seems to be a deeper level of understanding that allows Africans to put things into perspective including the scientific mechanism related to causality. It is clear that their understanding transcends causality to include purpose or function from a supernatural power. This in the researcher's view has made it possible for Africans to easily come to terms with what might appear to be an emotionally taxing experience of hearing that their child has DS.

Interestingly, they all appreciated the medical explanation of the condition and felt that it helped them distinguish between different types of conditions characterized by some form of disability.

*“We are grateful for the education we received about DS and how it is formed; we are better positioned to manage it now that we have the information.”*

*“The doctors gave us important information about DS. This adds to what we know... There is no conflict, all these information from our tradition and from the doctors is important.”*

They reported that a good understanding of the diagnosis and its prognosis is helpful as it facilitates the psychosocial healing process. They also added that the medical information contributes to the effective and efficient overall treatment and care for the child with DS. Some of the clans felt that such information about the diagnosis may assist in educating the broader community and raising awareness. In the long term, that might contribute in reducing the stigma and stereotypes generally held by the public on the basis of lack of information or little information. They shared this:

*“It is important for the family to know what DS is and what the cause is so that we are able to understand the child and assist accordingly.”*

*“I am very grateful for the information I received. I am now better informed about DS. They educated me and wherever I go I try to educate others.”*

*“There are too many misconceptions with the clans and the community. If the doctors and nurses were to share the information about DS more openly, not only to us as families, but also to the broader community, maybe it would help to reduce the stigma. Our children with DS are ill-treated by the community because community members do not understand what DS is.”*

A common sentiment expressed by the mothers participating in the focus group seemed to suggest that they are grappling with issues of stigma at community level. They reported that the community used different negative names and labelling to

describe the children with DS, some calling the children 'Zodwas' after a name of a special school in a Pretoria township of Atteridgeville, while others called them 'dihafi' (lunatics). They indeed admitted that learning that their children have a disability of some sort was a painful experience and that the negative reactions of community members added to the pain as highlighted by some of these comments:

*"While you are trying to nurse the emotional wound... the community come and add salt to that wound."*

*"My biggest source of pain is not the child and his condition, but the horrible treatment meted out at him out there. I keep asking myself, what will happen if God takes me away...I fear for my child. I have become so protective, I want him to play at home and never go far. The minute I realise he is not around I become worried."*

However, despite the medical explanations, the overwhelming majority still attributed the incidence of the birth of a child with DS to a supernatural being which is God or the Creator.

*"This is a gift from God and it is for a purpose, I am at peace with it."*

Some clans were fortunate to have their children tested to confirm a clinical diagnosis. A clinical diagnosis is based on observable clinical features consistent with DS whose results range from tentative to conclusive, whereas a test is used as a confirmatory option and the results are always conclusive as stated by Christianson et al. (2006:31). The clans found in the big cities such as Johannesburg and Pretoria in Gauteng province had better access to genetic clinics, support groups and diagnostic facilities and as a result the majority of them were tested and received counselling from genetic counsellors as well as referral to a support group. However, the counselling was given to the mother and sometimes together with the father or another significant other family member available. This was done at the hospital by the doctor or a nurse, followed by in-depth counselling by the genetic counsellor. None of the biological mothers or guardians interviewed in this study received assistance from a social worker at the hospital. Therefore, no social work counselling or psychosocial support through individual or group intervention was provided within a hospital setting. This is despite

the fact that almost all hospitals, specifically in Gauteng have social workers. One mother reflected as follows:

*“My child’s problems were picked up by the doctors at the hospital after birth. The doctor spoke to me and explained that the child’s features show that he has DS. He said they will take bloods to confirm and I was told later that the results confirmed that he has DS. I called the father and informed him and he broke down and cried saying that there has never been something like this in his clan. The doctor asked to see both of us and gave us the information and we were referred to the support group. The support group coordinator gave us counselling and we joined the group. We never saw a social worker ever since.”*

One of the urban-based grandmothers looking after her daughter’s child with DS and participating in the support group recounted as follows:

*“My grandchild was identified in the hospital by doctors and they did the tests to confirm the diagnosis. Her mother does not have a good hand for caring for a child and she is working. So I took over caring for the child and I was referred to the support group. We never saw a social worker at the hospital. The only counselling we received was by the doctor and a nurse and later the support group. I was very consoled by the support group when I saw other mothers with the same situation.”*

*“Sister ...a be a mo sheba mo matsogong, a mo sheba mo tlase ga mahlo...sister a re ngwana o re tlile go mo balela mo group ya bana ba ba sa itekanelang” (the professional nurse looked at the child’s hands, eyes and said that this child will be referred to a support group for children with disabilities).*

For the clans in rural areas, the diagnosis was based on a clinical examination of the child and identifying certain features by a nurse or doctor followed by more clinical assessments and, in some cases, a confirmatory diagnostic test. Below are several accounts given by mothers:

*“My child was born at home; he was sloppy and could not cry. He looked different from the other children I had. I realized something was wrong. Some in the clan insisted that*

*the child will be okay and there is no need to take him to hospital. We observed him, but there was no improvement and after six weeks I eventually decided to take him to hospital. They admitted him and we were there for several days and they were not saying anything to me until one morning the doctor came to me and told me the child has DS. It was the first day I heard about this name. He tried to explain that the child will be slow and he will not be able to function like any other children. This hit me hard emotionally. I informed my husband and he could not accept it and said his child is fine. I also told my mother-in-law. My mother-in-law came and looked at the child, but said the child is fine and he will be okay.”*

*“My child was born normally and afterwards when I took her to the clinic, the professional nurse at the clinic gave me a referral letter to go to hospital. I asked why, but they could not explain what the referral was for. I then took her to the hospital and they admitted the child. They later told me that my child has DS. They told me about her nose, ears and eyes that show that she has DS. They said she will not develop like other normal children and she may have heart problems. They also said she will be a slow learner and need a special school. I called my husband and told him and he said there is no such. There is a child next door who is also said to be a slow learner and goes to a special school. I used that child as an example to explain to the clan. The siblings have accepted and are supportive, but my husband even today has not accepted. Other clan members keep saying things like she is bewitched, but I am a Christian and believe in God. I believe she is a gift from God.”*

*“My child was very sloppy unlike other normal children long after birth. I got worried and took him to the hospital. I asked the doctor what is the problem with my child and he told me that the child will be okay, but it will take time. He is not severely disabled like the ones on wheelchairs but his development will be slow. I accepted, but never believed. I am a Christian, but I was tempted to go out and check with traditional healers. I visited one and she told me the child will be okay and gave me some muti, but when I came back and used them after a while there was no improvement and I decided to throw them away and went back to church. I told myself that this is my child, I love him and accept him as such.”*

*“My child was born in hospital but was taken away from me immediately after birth. When I checked with the professional nurse after two days about my child’s whereabouts they pointed me to a ward where the child was and I went to see the child. When I saw the child, she was very small. I then asked the professional nurse what was wrong with the child and she pointed me to the ears, eyes and nose, that confirmed that the child has DS. She explained that the child will develop slowly and will need a special school. She asked me to accept and care for the child. I was heartbroken and I informed her father and the rest of the clan. They did not believe me. I struggled with this until I was referred to a support group and I met other mothers with children with the similar condition.”*

From the conversations we had about the handling of disclosure of a positive diagnosis of DS at the hospital, which is tantamount to delivering bad news, there seems to be no established protocol and guidelines outlining the process as would be done with HIV testing and other serious conditions. The only place where there are protocols is within the limited genetic counselling clinics found in Gauteng. These clinics are organised regularly as stand-alone arrangements by appointment generated from existing prenatal and postnatal clinics at the hospitals concerned.

Therefore, the availability of related and necessary support services depends on geographic location, with urban areas at a better position than rural areas. All functional and well-resourced support groups are in urban areas. None of the existing support groups in rural areas are coordinated or facilitated by social workers. Instead they are coordinated by lay-volunteers. However, DS support groups in urban areas, particularly in Gauteng are facilitated and coordinated by the DSA directly in collaboration with officials from the DoH within hospitals. These are mainly professional members of the allied health professionals such as social workers, psychologists, physio therapists and occupational therapists. This is indeed consistent with a position propounded by Christiansons et al. (2006:31) when they argued that treatment, care and support for children with DS requires a well organised and coordinated plan by a multi-disciplinary team.

The parents and/or guardians of the children with DS reported that due to the fact that the bad news are delivered to them, they then have a responsibility to take the news to

the clan which in itself becomes a traumatic process. This is because often they themselves have little understanding of the condition and it is further complicated by the lack of African names and descriptions for DS and its features. Additionally, there are a number of society related stereotypes and stigma around congenital disability and mental retardation that the clan have to deal with. The stigma and stereotypes may either come from within the clan or outside. The participants in the focus group discussions expressed their desire for the disclosure of bad news to be done in a clan meeting with the significant others in the clan. They thought this would allow the clan to deal with the news collectively and to clarify some of the myths and misconceptions about the condition as well as discuss what can be done going forward. The participants from clan interviews echoed similar sentiments. The opportunity for clan discussion according to them will go a long way in ensuring that the clan speaks in one voice about the condition and that they are able to pool resources both personal and material to support the child going forward as seen in the following verbatim accounts:

*“The most difficult experience after hearing that my child has DS was that of having to explain to my husband and the rest of the clan. I was confronted with denial and it took time before my husband and children accepted, I feel that if the information was given to the clan, it would have made things easier for everyone.”*

*“My husband is still adamant even today that the child does not have DS. He does not accept it at all and I do not know what to do. He does not even want to attend the support group.”*

*“I did not know what DS is. I only heard it for the first time when the doctor explained. Then I had to go and explain to the whole clan about DS with my limited knowledge. It is a serious problem. I wished they could have given the information to the clan.”*

The significance of the above statements is two-fold. Firstly, it talks to the need to approach the African clan system differently given its unique attributes and sharp contrast with the western social organisation. As affirmed by Brydon (2011:160) social work scholars should be challenged to move beyond the proverbial notions of cultural sensitivity and competence and embrace cultural relativity in order to appreciate different cultures and ways of viewing the world. If social workers were to appreciate

different cultures, they would be able to approach African clans in a more culturally relevant manner that considers the collective nature of its functioning. Mupedziswa (2001:293) argued that social work in post-colonial contexts such as Africa remained entangled in a struggle for relevance because its content and outlook remained imbedded in first world principles and approaches. In view of the above situation in Africa, some scholars have challenged the profession of social work to return to its original domain of structural change and social justice (Smith, 2008:374; Sewpaul & Holscher, 2004:39). This would allow for a more broad-based social transformation across the spectre including how other cognate and allied professions within the multi-disciplinary team operate.

Secondly, the statements by the participants talk to the inherent challenges of stigma related to disability amongst African clans. There is a stigma attached to giving birth to a child with congenital malformation or mental retardation as found in DS among African clans (DSD, DWCPD & UNCF, 2012:45; Rosenkranz, 2004; Christianson et al., 2002:180). Amongst the African clans, such a birth is widely viewed as a curse by the ancestors for some form of misdeed either by the parents or by the clan as a whole (Christianson et al., 2002:180).

Some of the biological mothers reported negative reactions from significant others in the clan including outright rejection of the child with DS as not belonging to the clan. Four participants reported that their partners rejected the children and questioned their paternity.

*“My husband was very aggrieved on hearing that the child is not okay, he rejected the child and claimed that in his clan there has never been a child like that and as such it cannot be his... we eventually separated. Up to this day, he is gone and I am struggling with the child alone together with the siblings. But I accepted and said God knows where this is going.”*

*“My husband became angry with me the time I informed him that I am pregnant with our fourth child. He told me he did not want another child and when the child was born and had medical problems, he became worse and decided to desert us.”*

*“When I informed my husband about the child’s condition, he turned against me, blaming me for the child’s condition. He accused me of not observing certain traditional rules and ceremonies. For a very long time he was not supportive and even questioned the paternity of the child. The clan had to intervene to try to reconcile us and he eventually decided to accept the child and he is now supporting me.”*

*“I am not married to the father of the child. After realising that the child has problems, he disappeared. I had to suffer alone, running around trying to find medical care for the child and he was nowhere to be found. I then realised that this is my burden alone and never bothered to chase after him. I am grateful that the Lord revealed his true colours. I love my son and I am doing my best to look after him.”*

The above statements further confirm what the literature indicated about the stigma attached to giving birth to a child with congenital malformations and mental retardation as found in DS among African clans (DSD, DWCPD & UNCF, 2012:45; Rosenkranz, 2004; Christianson et al., 2002:180). It also highlights the need for social work intervention to assist the members of the African clan to come to terms with the realities of raising a child with DS. It is therefore imperative that the African clans raising children with DS be prioritised for psychosocial support at all levels in the continuum of care. This may include consideration for early intervention as provided for in the framework for social welfare services (FSWS) (DSD, 2013:27). The FSWS defines early intervention services as services focusing on the early identification of risks, behavior and symptoms in individuals, groups and organizations that, could negatively impact on social well-being (DSD, 2013:27).

Furthermore, it has been shown in the literature that stress reactions and grieving by significant other clan members may feature amongst the possible implications of raising a child with DS (Kinman & Jones, 2005:115; Aldwin, 2007:118). Thus, the negative reactions displayed by some of the members of the clans, particularly fathers as reported by the participants may have resulted from the typical stress reactions experienced by the individuals concerned. The literature confirmed that stress reactions will differ even between individuals exposed to the same stressor depending on how they are appraised and the reactions may manifest as solution-focused or emotion-focused coping mechanism (Kinman & Jones, 2005:115). The appraisal

depends on the individual or clan's capacity to deal with the demands of the stressful situation where better capacity leads to better coping whereas lack of capacity may lead to more overwhelming degrees of stress reactions (Kinman & Jones, 2005:115). Thus the incidence of fathers' rejection of the child with DS may be a permanent solution-focused coping mechanism or may represent a temporary emotion-focused coping, where the father avoids contact with the situation until such time they are prepared to face it. Kinman and Jones (2005:115) asserted that sometimes, negative appraisal may be attributed to lack of information. Thus, the availability of psychosocial support and other forms of aid may go a long way in helping the affected members of the clan deal with the challenges to avoid resorting to any dysfunctional coping mechanism.

Additionally, some of the reactions reported can be best explained using Kübler-Ross's grieving process as explained by Chapman (2013). The birth of a child with DS instead of the expected 'normal' child triggers a grieving process amongst members of the African clan as they attempt to come to terms with the loss of normalcy. Therefore, the ability or capacity of the clan to access accurate information and psychosocial support may hold the key to better coping strategies. However, dealing with accurate information requires that one is emotionally stable to contain such information. Therefore, the provision of medical information at the health care facility coupled with psychosocial support is important throughout in order to assist with appraisals, provide tangible support including both practical aid and provision of needed information (Kinman & Jones, 2005:115; Aldwin, 2007:118).

Consistent with 'denial' in the grieving process, some participants reported that their partners/husband reacted negatively after seeing the child with DS. They said:

*"... as soon as he saw the child with DS, he reacted with shock and claimed that in his clan, there has never been a child like that and therefore the child is not his."*

At least two of the four participants in the support groups whose partners rejected the child with DS and questioned paternity ended up with a broken marriage, leading to separation and divorce. The partners reported as follows:

*“... my husband worked far in the mines and only came home after two weeks... After complaining about the child he started skipping three weeks up to a month and eventually decided to come home and pack up his personal belongs and left us for good.”*

*“... my partner left immediately he realised the child was not well while in hospital. He then disappeared and never kept contact.”*

However, some partners (husbands) who held the same view in a positive manner without rejecting the child denied the disability of the child. They maintained that the child with DS will be fine eventually as there has never been a child with disability in their clan. They resorted to using their clan names, totems and praises to proclaim that such forms of disability and the spectrum of clinical features as explained medically in the context of DS cannot occur on one of their own. Participants had this to say about their husbands' reaction to the news that the child has DS:

*“After informing my husband about the child's condition that he has DS, he responded by saying...he is a 'Maepa' and he will be ok.”*

*“My husband, never accepted the diagnosis, he insisted that his child is fine.”*

In some cases, even other clan members expressed negative views about the child with DS as shown below:

*“My in-laws told me there was nothing like that... after I explained to them that the doctors told me that the child has DS. They insisted that there has never been such in their clan.”*

Some clans were not negative, but insisted on a traditional view in dealing with the child with DS as shown in the verbatim response below:

*“As a clan we needed to get together in a ceremony to inform our ancestors about the situation of the child. It is also custom that we consult with our ancestors for guidance. Issues like these are normally dealt with by elders in consultation with our ancestors.”*

*They will guide us through this. We do not reject the doctors' explanation, but we also have to deal with it traditionally."*

The above statements can be attributed to the denial stage in the grieving process (Chapman, 2013). When the husband denied outright that the child does not have DS despite the diagnosis given by the doctors, it points to denial as a stage in the grieving process. It also points to emotion-focused coping where the individual chooses to cope with the emotional reactions of a stressor through "avoidant" coping strategies as indicated by Aldwin (2007:117). The example of the one husband who said that his child is a 'Maepa', he will be fine, demonstrates a sub-category of avoidant coping strategies known as "escape-avoidance" according to what has been said by Aldwin (2007:117). The husband employed escape-avoidance by attempting to escape from the stress through wishful thinking when dealing with a stressful situation of the birth of a child with DS.

Some of the participants in the focus group were referred by either a nurse or doctor to the support group immediately after the diagnosis was confirmed. The support groups in urban centres were very active and strongly present in hospitals, running sessions regularly and doing outreach programmes, whereas in rural areas they operated outside hospital, but in the community with no direct relationship with hospitals, except that the hospital would refer new mothers. Hospitals did not have any link with the support groups or coordinators.

*"We organise ourselves and run the support group on our own. We used to receive some help from the Down Syndrome Association national office, but they have since handed over to us to run on our own. The hospitals do not help us, we do not have any offices, we meet in this community crèche and we recruit new parents that we identify in the community"*

*"Our support group is run at the special school, we were assisted by one of the parents who is an advocate to start the support group and we came together to support each other, to this day we do not have any support from any government institution. We used to receive some financial assistance from the Down syndrome Association, but have since stopped. We are on our own"*

This sub-theme was about the manner in which the African clan received the bad news about the diagnosis of their child with DS. Evidence from the data shows that the information about the diagnosis was given mainly to the mother at hospital. In some cases both parents (mother and father) were provided with counselling and given the information together. There were varied reactions to the news with mothers enduring the stress and grieving arising out of the disclosure of bad news about the child's diagnosis. Some fathers, particularly unmarried fathers, decided to abandon the child and the mother. However, some fathers were able to stand by their wives and children despite resorting to various dysfunctional coping mechanisms such as denial and "escape-avoidance". They relied on wishful thinking to avoid focusing attention on the real issue of the diagnosis of their child with DS. It would seem that psychosocial support and provision of information was instrumental in helping the mothers and the clans come to terms with the situation. They belonged to a support group that provided emotional support as well as information about DS. It could be more beneficial if the clans would receive structured psychosocial support from the social workers. The next theme focuses on the African clan's coping strategies with regard to raising a child with DS.

### **Sub-theme 2.2: The African clan's coping strategies with regard to raising a child with DS**

The parents and clans confirmed in the interviews that although they accepted the condition of their child with DS, the realisation that their child has an abnormality was a shocking and traumatic experience for them and the clan, as shown below:

*"I was heartbroken, I started questioning God, asking: why me?"*

*"I was devastated at first, did not know who to turn to for help, out of desperation, I ended up even going to consult a 'sangoma' although I am a Christian, just to make sense of this experience."*

*"It hurts so much, especially when you do not have support at home, my husband was also devastated and resorted to shifting the blame... it worsened the situation."*

This confirms earlier assertions in the literature that the identification of an abnormality in a child is a shocking experience for parents (Cowles, 2000:13). The above reactions are consistent with Kubler-Ross's stage 1 (denial and isolation) as well as stage 2 (anger). As argued by Chapman (2013) denial and isolation is the initial reaction and a defence mechanism that buffers the immediate shock. Subsequent to this, anger may be directed at self, God or others especially those close to them.

Therefore, in the context of the African clan raising a child with DS, there was a large amount of scope for potential stress. The challenge of raising a child with disability as experienced by African clans raising children with DS in this study evoked varied responses or reactions emanating from the pressure exerted on the clan system by the lived reality of raising a child with DS. Indications from data showed that the birth of a child with DS is disruptive in the life of the African clan system. Also, the attendant stress reactions do alter the state of equilibrium of the clan system depending on how the clan deals with the stress reactions. This is evidenced by numerous marriages and relationships that broke down as a result of the birth of a child with DS as well as divisions in the clan about what caused the condition and what intervention is needed. Some clan members who were inclined to traditional practices preferred the challenge to be addressed through traditional measures while others who subscribed to the Christian faith preferred dealing with it using Christian spiritual approaches.

The notion of stress conceptualized by Van der Merwe (2004:14) is consistent with the ecosystems perspective as it covers anything that causes impairment and instability in the balance and/or homeostasis of the affected system (in this case the African clan system). Therefore, using the ecosystems theory as an analytic lens to illuminate the effects of stress on the African clan raising children with DS, one considered the possibilities of reactionary adaptation by members of the African clan raising children with DS as they attempted to move towards a state of equilibrium following the disruptive effects associated with the unexpected birth of a child with DS. A proper analysis of stress should break it up into the appraisals made of environmental demands, and the resources available to cope with the said demands and the demands should be made separate from individual responses to them (Kinman & Jones, 2005:101). Indeed, as shown by the data, different clans reacted differently to the same experience under seemingly similar capabilities and resources. Thus, the

varied reaction by varied clans of children with DS to the experience of raising the children can only be attributed to how they appraised the demands as a determinant of how they responded to them. Kinman and Jones (2005:101) explain that a negative or positive appraisal will determine how a person deals with a stressful situation regardless of whether they have the capacity or resources to deal with it.

For instance, the data revealed that some clans accepted the experience of raising a child with DS as a will of God with a good purpose. The data also showed that these clans were better placed to find the experience positively fulfilling and joyous and consequently easy to accept, whereas those who viewed it negatively got stuck in misery and dissatisfaction emanating out of being thrown out of balance by the disruption caused by the birth of a child with DS.

Firstly, the birth of a child with DS presented life pressures that placed demands on the clan system, resulting in stress reactions of varying magnitudes capable of throwing the clan system out of balance. The ecosystems perspective allowed the researcher to map out various sub-systems within the clan system affected by the disruption including the couple, the sibling's sub-systems and the significant others. New demands on the clan system and the lack of capacity within the system to accommodate the demand placed upon it by the birth of a child with DS led to the loss of equilibrium and homeostasis. Secondly, the stress experienced by the clan manifested positively and /or negatively depending on how the clan handled the demands (the stressors) of the birth of a child with DS. When the clan failed to handle the demands appropriately, the stress became negative (a clan member's inability to accept the child with DS/disability). Conversely, if they managed to handle the stressors well, the experience of stress became positive.

For instance, we see in the response below that once there was acceptance, the clan's experience became positive:

*“Regardless of the rejection by my husband and some other clan members, I love my child and accepted her. I started experiencing a sense of appreciation to God for blessing me with such a beautiful soul. She is a lovely child and everyone loves her. Even all those people who were negative now love her so much.”*

Acceptance is the final stage in Kubler-Ross's grieving process as outlined by Chapman (2013). It is characterized by emotional detachment and calm. The above response illustrates an example of an individual who has reached the stage of acceptance. She seems to have made peace with the situation, whilst the other family members including the husband seem to still be stuck in denial.

Furthermore, it is worth emphasizing that the demands were placed upon the clan's capacities. The clan's capacities and available resources to deal with the demands determined how well they responded to the experience and whether it was eventually seen in a positive or a negative light. Indications from data are that different clans experiencing the same demands at different times responded to the demands differently, and this may be attributed to their different capacities from time to time. For instance, some of the African clans reacted differently to the experience of raising a child with DS before and/or after receiving psychosocial support and counseling in this regard as shown below:

*"I was devastated until I was referred to a support group and as soon as I started interacting with fellow parents with a child with DS, I started seeing it differently and this helped me to heal."*

*"I was consoled by the support group and I began accepting my child with DS."*

The above statements demonstrate how mothers were able to move from the earlier stages of denial and isolation, and anger to bargaining according to Kubler-Ross's grieving process as outlined by Chapman (2013). The support group seems to have played an instrumental role in their bargaining process as shown above.

The data also showed that it was not always the actual events, nor the person's capacities and resources or lack thereof which determined whether the clan experienced stress or not, but rather the manner of appraisal to the stressor as postulated by (Kinman & Jones, 2005:101; Aldwin, 2007:115). This observation confirmed earlier findings by the above authors that stress may be a function of the appraisal of the stressful situation.

The clans did not respond to the experience of raising a child with DS the same way. It was not necessarily the birth of a child with DS that was stressful, but possibly the perception of the clan about the meaning attached to having a child with DS. The social constructionist theory provided an effective theoretical lens through which the researcher analyzed how the resultant collective perceptions of stigma associated with DS was constructed and internalized. In the same vein, the theory provided an alternative for deconstructing bad perceptions and constructing better ones that may enable the families to move forward in cases where they were thrown out of balance and got stuck.

Finally, Ambrosino et al. (2008:217) in line with the social constructionist theory developed a new concept known as 'social stress', enabling us to expand our understanding of stress beyond the personal thoughts and emotions. The social stress perspective, based on the work of Szasz (1998) cited in Ambrosino et al. (2008:217), emphasized the relationship between the environmental stress and mental health. This perspective suggests that individuals who are under duress including the poor, people of colour and women, are more likely to develop mental health problems. The African clans raising children with DS fall under this category and their experience of dealing with the challenge of raising a child with DS were viewed as a double blow in addition to their inherent existential social conditions predisposing them to stress and mental health problems. This was illustrated when the data showed that the traditional African clan had a rich cultural heritage underpinning its worldview, but the social structures and systems surrounding it did not support its worldview as they were antagonistic towards it. Interviews concerning the professional practice of social work show that, although not directly shown in the study as the African clans raising children with DS interviewed in the study did not receive social work support, social workers did provide adequate insight leading to the conclusion that the social work profession is expected to be part of the team that supports the African clans raising children with DS. This is, however, based on a different and conflictual worldview (western worldview) and used theories, approaches and techniques that were alien to its context resulting in it perpetuating rather than alleviating its stress.

In line with the interview guide, participants were asked how they made sense of the birth of a child with DS. The participants reported that it was difficult to come to terms

with the experience, but eventually accepted it as a gift from God and gods or ancestors. This sentiment was shared across the clan interviews and the focus group discussions. However, a few evoked ancestral issues while some attributed it to witchcraft. As per the definition of coping discussed above, the responses of participants reflected a transaction between the clan and the demands in the immediate social environment of the clan brought forth by the birth of a child with DS. Additionally, the data show how the clan appraised the situation, understood the cause and attributed it to a particular purpose and function. For example, some had these to say:

*“I appreciate the medical explanation from the doctors about the cause of DS, but I know God did it for a purpose.”*

*“I accepted my child as a gift from God, the medical explanation is important for me to know how to manage the condition, but God has a purpose with this.”*

*“I was devastated by the news and out of desperation I wanted to find out from a traditional healer if my child was not bewitched.”*

*“Other clan members believe that my child is bewitched and we needed to seek some intervention from the traditional healer.”*

An interesting point worth mentioning is that all of them, regardless of their religious affiliation or belief system reported that they relied on and would seek intervention either from an African traditional or Christian healer/diviner for routine protection and /or when confronted with a serious problem. Some participants reported that it took time for the clan to adjust and learn to live with the child with DS. Each one in the clan had their own explanation for the occurrence of the condition ranging from spiritual to punishment for transgressions by parents. This brings to the forth an important aspect in the manner in which Africans deal with the occurrence of disruptive incidences in their lives. The researcher deduces, on the basis of the data presented, that Africans tend to focus on three aspects, namely: causality, purpose and function.

Firstly, there was general consensus amongst participants, particularly mothers who were informed by the doctors and nurses about the aetiology (causality) of the condition that such information is of great value in helping them understand and its management. They expressed gratitude at the medical explanation of DS. Secondly, they maintained that the incidence of the birth of a child with DS was not sporadic, but purposeful. They attributed the purpose to God or ancestors/gods as shown below:

*“While I appreciate the medical facts, I am mindful of the fact that God has a purpose with this. He gave me this gift of a child with DS for a particular purpose and it will become clear as time passes.”*

Thirdly and linked to the above, is the fact that participants believed that there is a function that the birth of a child with DS seeks to perform in their lives as shown below:

*“I believe God wanted to open doors for me through this. I lost my job just before this child was born and when the child came and she had DS, I was linked up with the special school and eventually was offered employment at the special school as a care giver. So God wanted to secure my future and used this child to do just that.”*

Another mother revealed that she did not believe in God until her son with DS was born and her clan including her mother rejected the child leading her to wonder around trying to find help until she became a Christian:

*“Through this child I got to know who is really on my side, my clan dumped me including my own mother. While wondering around helplessly, I found God and surprisingly my child is also spiritually gifted. I believe he can prophesy and I was told at church to watch him. He knows when church time is and he participates actively. It is amazing. I have come to discover so many things through him. Sometime when he is given food, he just refuses to eat and I realise in hindsight that there might have been something wrong... you see God is working in my life through my son with DS.”*

In all these difficulties, none of the clan and members of the focus group saw a need to consult a social worker. They resorted to established social support systems found within clans. Older mothers took full care of their children with DS, whilst younger once

gave their children over to their parents or 'mmangwane' (mother's sister/aunt) if biological parents were not there. Other younger mothers who had a child with DS gave the child over to their elder sisters and grandparents.

*"I was never assisted by social workers throughout and never thought of them helping, I consulted with members of my clan as well as my pastor at church."*

*"I am a Christian, so I prayed about it and spoke to my pastor, but I also consulted the 'sangoma' following the advice of my clan."*

*"I spoke to people in the clan and the elders were very helpful, I never received any help from social workers."*

While some of the members of the clan took an initiative to consult with elders in the clan system about the child's condition some did not consult, but all of them reported that various elders were concerned and gave their views on the condition of the child, particularly 'vokokwane'(grandparents), 'vohahani'(aunts) and 'vopapakhulu na vopapatsongo'(junior and senior fathers). Meaning that the paternal side of the clan in the case of married couples were all interested in the matter and sought some form of intervention, as reported by some mothers:

*"I do not believe in consulting 'sangomas' or using 'muti' as I am a Christian, but my in-laws do. They went out to consult a 'sangoma' and came back to give us feedback. They advised us to perform a traditional ritual and ceremony that will involve slaughtering a beast (cattle) or goat to appease our ancestors. They were convinced that the child will be okay."*

*"My husband together with my in-laws did go out to consult a 'sangoma' and he came back with some 'muti' which he used on the child."*

*"My clan including uncles and aunts advised me to ask my in-laws to do a ritual and ceremony, but my in-laws are Christians, they do not follow such things."*

The participants as shown above reported that other clan members called for '*lesiko or isiko*', which is a traditional ceremony to petition the ancestors to intervene and help the child, while others who were more inclined to Christianity tended to rely on the Holy Scriptures for guidance. The above findings show that the news about a child with DS was received differently by different clans depending on their level of education, cultural and spiritual background and different coping mechanisms were used to deal with the situation.

As indicated earlier, there was no African name for DS. The above data could be understood as a reflection of what Aldwin (2007:115) referred to as cognitive approach to coping. In order to make sense of the data coming out of this study regarding the coping mechanisms employed by African clans to deal with challenges associated with raising a child with DS, the researcher used the cognitive approach to coping with stress as a tool to analyze the data. The cognitive approach assumes that an individual is flexible with regard to their coping strategies, and can adapt and modify these strategies as the demands of the stressors change (Aldwin, 2007:115). This implies that coping is not a uniform, static activity, but rather one that changes from person to person, as well as from stressor to stressor, and environment to environment. Discussions in the literature review show that the cognitive approach conceptualizes coping as comprising two strategies which are: solution-focused and emotion-focused coping.

The above coping strategies as conceptualized by Aldwin (2007) from a Eurocentric worldview, views coping as a personal psychological reaction to a stressor. However, for the Africans, coping is viewed from a collective social constructionist viewpoint. The social constructionist perspective of reality highlights that the social reality we experience around us is "invented" and we assimilate and accommodate new knowledge from the environment to invent it (O'Connell, 2001:22). Meaning that when people encounter new experiences and by implication, new knowledge, they are changed by it and in turn adjust to the new experience. As shown by the data, the clan as a collective uses its established knowledge systems to deal with the experience of raising a child with DS. In the process of dealing with the challenges of raising a child with DS, the clan develops new insights including learning about the etiology of the DS condition, the spiritual aspects and affective ways of knowing emanating from the

experience of raising a child with DS. Some of these aspects of learning are collectively shared across the clan as reflected in the response below:

*“As a clan we knew nothing about DS, we had never encountered it before. It has never happened in our clan. We appreciate the knowledge shared by the doctors about the origin of DS. It has added to our knowledge. We believe that God created everything we see and experience. Sometimes the things he creates we understand and can explain how they happen, but sometimes we lack the knowledge, but he also gives us the wisdom to find that knowledge as he did to the doctors. We cannot argue with him and say this should not happen to us. Who deserves it? It has to happen to someone, but there is a bigger purpose behind it. It is not a nice experience, but in it we get to learn and appreciate his power and love. We have grown stronger and closer through this experience. We are in a much better place than we were before.”*

The above response reveals that the experience of raising a child with DS brought forth a series of learning opportunities and challenges. The clan learnt to pool resources and pull together through the experience. This occurs more overtly at a collective level, although it could also be argued that this would have started at an individual level though less pronounced forms of personal transformation and growth were echoed.

*“Each one of us in the clan is different, so we learn differently and at different paces. But we all learn, both as a collective and as individuals. The child also taught us a lot of things. We now know how to treat the child and how to communicate with her as a clan. People from outside find it difficult to interact with the child because of her speech problem, but we know how to talk to her and she has her way of communicating to us. She also knows who amongst us assist her to meet a particular need. For example if she is hungry, she knows who to tell.”*

This is consistent with the social constructionist perspective on collective learning and knowledge development as well as the social constructivist perspective on personal learning and knowledge development.

In line with the ecosystems theory, the clan raising a child with DS tends to lean on to some sub-system (elders) within the clan to talk through the experience so as to make sense of it.

*“We relied heavily on our elders to guide us through the challenges. We believe they have the knowledge and wisdom.”*

Additionally, the birth of a new child with DS in a clan necessitates that feedback loops in the entire clan system be activated and observed closely. Depending on circumstances, such feedback loops may direct the clan in a manner that has the potential to reset the parameters of the clan to cope with a new young member of the family with DS. For example, a particular household in the clan may find it sensible to no longer play their music loudly and rather opt for softer music so that the child is able to sleep peacefully, hence resetting boundaries in the particular household.

Through the use of the ecosystems perspective, the researcher was able to conceptualise how the birth of a child with DS alters the balance that exists between growth and regulation within the clan. This observation led the researcher to appreciate that the objective of social work in cases of clans raising children with DS should be to enhance and promote better relations and interactions between elements and sub-systems within the broader clan system and its environment. This will be done in such a manner that will enhance social functioning and effect the required balance/equilibrium between the clan system and its environment. The eco-systems perspective was effectively used from an Afrocentric perspective to identify, explore, and analyse various systems and sub-systems that are connected to and make up the typical African clan system. The perspective also enabled the researcher to analyse the relationship dynamics between the pertinent social, spiritual and natural/environmental subsystems, including the nature of influence exerted amongst the sub-systems, such as the couple sub-system, the sibling sub-system and the extended family sub-system, as well as the individual sub-system in each sub-system outlined.

This is better illuminated by the solution-focused coping process. One of the first steps in the solution focused coping process is to begin with a “narrative” account of the

stressful experience (O'Connell, 2001:24). As the African clan raising a child with DS gives their own version of events, they begin to decipher which version of the story, with regard to the stressful experience of raising a child with DS is the more accurate and acceptable, as there will be several versions or perspectives of events. As seen in the data, these may include the information provided by the doctors, nurses and genetic counsellors at the hospital, the actual observable features of the child and some practical experiences with the child, the views of the community and the broader society as well as various versions of clan narratives.

This is shown in the statements uttered by participants below:

*"The information about DS was given to me at the hospital. I then had to explain it to my husband and to the entire clan."*

*"Explaining DS to the clan was my most difficult task when I got home. Part of the difficulty was that there was no word for DS in our language."*

*"I could see that there was something wrong with the child, she was sloppy and looked different from my other children."*

*"My husband dismissed everything I told him about DS as explained to me by the doctors, he convinced himself that there is no such and that the child will be fine."*

*"The clan was divided on this issue of the child with DS, some attributed it to the ancestors, some said it was witchcraft, some said we should conduct a traditional ceremony and others even thought it was because of something I did."*

Additionally, there was also a myriad of common explanations based on societal perceptions and stereotypes for causal factors of congenital abnormalities and disabilities as shown below:

*"There is a stigma associated with children born with mental challenges. People tend to think that it's a curse."*

*“The communities tend to frown upon children born with disabilities, labelling them negatively and often try to find something negative to say about the clan that led to the child being born with a disability.”*

*“It took time before we could let the child go out and be seen because we feared for his safety and our own, the community can be horrible sometimes to children like this. They sometimes don’t even want their children to have contact with the child and they ill-treat him.”*

As we would know and understand from the African worldview and cultural thought, there was also an aspect of spiritual and affective thoughts. The clan had to deal with different subjective narratives from within the clan and outside. The process is called differentiation, and then integration of a truer, more utilisable narrative (Knight, 2005:155). This process can be very helpful in assisting the African clan form a less subjective perception of the problem through conversations. Through a series of back and forth conversations, the African clan seems to have worked through and perceived new options or alternatives with regard to developing a common understanding and solution to the stressful challenge of making sense of the child’s condition. They do this in the midst of common, dominant and counter narratives about DS, congenital disability and mental disability.

For instance, a common phenomenological narrative amongst the African clans interviewed was that a child with DS is ‘sweet and friendly’, and that it is a ‘gift’ from God that must be appreciated and cherished. This developing narrative out of their lived experience occurred against a backdrop of negative sentiments and stereotypes about the stigma associated with raising a child with disabilities. Consequently, some families got to accept and cherish the unique personal qualities of their children with DS quicker than others. Some African clans struggled to get to the point of acceptance due to challenges associated with managing different and often conflicting narratives as shown in the statement below:

*“It was a messy and confusing journey, one minute it feels like it’s getting better and you are getting used to the child and the other minute it’s all negative and miserable with all sorts of negative things being said about the child, that he is a curse, he is a*

*burden and he will never grow to become like others by getting educated and successful and you wonder why us, what have we done to deserve this?"*

According to O'Connel (2001:26) the next step in the solution-focused process is about the possible cause of the problem. This is a continuation of conversations and narratives, but at this stage the conversation narrows down to a specific causal factor instead of generalized conversations as seen in step 1. The conversation at this stage is about 'causality'. The data shows that the African clans contemplated various possible causes or origins of the child with DS. The data shows various ways in which different individuals, households and clans explored on their own, possible causes of the birth of a child with DS; some may be viewed as helpful while others may be viewed as not so helpful. As indicated earlier, there was consensus amongst participants that, despite few objections from some in the clan, the medical explanation regarding the origin of DS was generally accepted. Even clan members, who initially rejected the medical explanations, eventually accepted them. However, the participants had other ways of explaining and making sense of the birth of a child with DS in addition to the etiological explanation. Some pointed to the incidence as the will of God, while some believed that it might have been due to witchcraft or ancestors.

In addition to the stress reactions associated with attempting to make sense of the incidence of the birth of a child with DS, African clans also contemplated the cause of various stressors that arose with raising a child with DS and its associated social challenges and medical complications. The understanding of a cause was logically followed by an exploration of what can be done to ameliorate the problem in line with an appreciation of the origin of such a problem. For instance, they all understood the cause of DS to be beyond one's control, then the clan worked towards accepting it as it is beyond their control and their focus shifted towards trying to come to terms with and adapting to the new situation.

The data showed that some of the African clans grappled with challenges associated with raising a child with DS, such as the need for regular medical attention due to complications, challenges finding special schools, challenges associated with bad treatment of the child by others, etc., as articulated below:

*“It was not easy, the child is sickly and I am always in hospital.”*

*“You have to make sure there is always money available to take him to hospital and to be there with him.”*

*“My child needed heart surgery, and they could not do it in Potchefstroom. I had to travel to Baragwanath Hospital from the North-West province on several occasions before and after the operation. I had to stay there for almost a month with him for the operation.”*

*“It is not easy at all; you suffer a lot as the mother, firstly from all medical complications followed by difficulty finding a special school. You don’t find the special school around, so you have to travel to other areas to find a special school and once you find one, the struggle begins to fight for a space there. It’s a constant struggle, there is no peace. Once he is there, it’s all the trouble with them being ill-treated or management complaining that the child is not doing well...”*

In this case, their ability to identify and list all of the specific causes or drivers of their stress enabled them to better understand the causality of the presenting stressor as well as link it to other stressors.

The third step in the solution-focused process is the reassessment of self-image. This step has to do with the image the African clan had of themselves following the experience of raising a child with DS. Within this process, stress can be seen as arising from a disparity in the way they view themselves, and the manner in which they would like to be viewed by others (O’Connell, 2001:29). This illustrates the conflict between their ordinary self and their idealised self. This evoked feelings of guilt, self-blame and anxiety in the case of African clan raising children with DS. It was necessary for the clan to be able to bring these two “selves” together. They had to start exploring their inner perception of themselves in relation to their outer world. In this way, the family could begin making links to their own inner perception of themselves and the consequences this perception has on the outer world around them. In this manner, the presenting problem or stressor was given a social or environmental context by the clan. This context could be used to work towards a solution for the problem. For instance,

one of the participants mentioned that her husband on hearing that the child has DS and all associated disabilities he said:

*“This is a Maepa, he is going to be fine.”*

In other words, the husband used his own inner perception of a ‘Maepa’ child as a perfect child that can never have disabilities and refused to accept the reality that the child has disability. In this case, the image and context given is problematic as it is based on denial as outlined by Chapman (2013) and therefore prevents the parent from working on a realistic solution to the stressor, but instead allows him to adopt a dysfunctional coping mechanism of denial.

Furthermore, another interesting common aspect coming out of the data is the spiritual practice known as the ‘lesiko’, a ritual performed by the clan to present prayers and gratitude to the ancestors. It is interesting to note the fact that the paternal clan hold power and control over it. The maternal clan can only advise that it be done, but is never conducted by them. They have to ask elders from the paternal side including the aunts and senior/junior fathers to facilitate the process of ensuring that it gets done, as shown in the statement below by a married woman who was advised by her own aunt (junior mother/younger sister to own mother in African cultural terms) to ask her husband’s aunts to consider ‘lesiko’:

*“My aunt came to see me and saw the child. She immediately said that we need to conduct a traditional ceremony (lesiko) to communicate our challenges to the ancestors. She said that she does not have the powers to initiate this as it rested on the shoulders of my marital clan. They must do it as the child belongs to them. She advised that I speak to my husband to invite his aunt (father’s sister) to come so we can discuss the issue with her.”*

Another participant alluded to the significance of traditional ceremonies such as ‘lesiko’ and explained as follows:

*“Lesiko is a common spiritual practice that is invoked when something pleasurable is achieved such as achievement of milestones including marriage, birth of children and*

*career promotions. The ritual is also performed when something bad befalls the clan such as loss of employment, conflicts and family feuds, deaths, accidents and the birth of a child with DS. These events are reported to the elders and they make a determination as to whether they require a ritual or other traditional practices such as consulting a traditional healer. When the ritual is performed all clan members are brought together to be part of the ceremony.”*

Some of the participants, particularly the mothers of the children reported that the maternal clan was also concerned and made their views heard about what they thought caused the child to be born with DS. However, such concerns were communicated through to the mother of the child and not directly to the clan. However, in single parent households led by an unmarried woman, the maternal clan took charge of the situation through ‘vokokwane’ (grandparents), ‘malome’ (uncles) as well as ‘mhaninkulu’ senior and ‘mhanitsongo’ junior mothers.

A considerable number of members of the focus groups in the North-West province spoke about a phenomenon known as ‘kgaba’.

*“This refers to a spiritually transferred bad omen by one’s enemies who do not wish the pregnant mother well for her pregnancy. Their negativity becomes a prayer that gets answered when the pregnant woman ends up with a baby with disabilities or a miscarriage”*

It is reported that amongst the Batswana people, this phenomenon can be healed through an intervention by an experienced traditional healer who prescribes certain traditional medicines that casts out the ‘kgaba’. They reported that, elders in the clan are able to pick up signs that the phenomenon possibly exists and make necessary interventions on time to prevent it from destroying the pregnancy. Some mothers in the focus group hinted to the possibility that their giving birth to a child with DS might have been due to ‘kgaba’. There was general consensus that this phenomenon is real and can be treated using traditional medicine which is also known as ‘kgaba’. Others believed that spiritual interventions, especially Christian faith, are also capable of casting it out.

*“With all my pregnancies, I make sure that I go to the elders or traditional healer to prescribe ‘kgaba’ for me. I did not take ‘kgaba’ with this pregnancy and I think maybe that is why I ended up with this child.”*

*“I am a Christian and use prayer to deal with ‘kgaba’.”*

Most mothers interpreted the experience of giving birth to a child with DS spiritually. To them it meant something or it was a way of communicating a message from God. Some viewed it negatively saying it was a warning sign or a way of reprimanding them following some transgression against the clan and its ancestors, while others particularly those using Christian spirituality saw it as a way of preparing the mother and the clan for greater blessings and positive things to follow. Some mothers reported that they had lost their jobs and source of income, but the child came with a grant and the rest of the household survived on such a grant while another mother said that she separated with her husband who was a bread winner after learning that the child had DS and soon after that experience, the special school for children with disabilities offered her a permanent job position as a general assistant and she is now the bread winner for the rest of her household. For her, the birth of a child with DS was a blessing in disguise and her believe is that God was preparing her for a social and financial upliftment for which she is very grateful.

Another mother reported that because of the challenges she had with the child with DS, she ended up at church and her life changed for the better as she found God and since then she has seen many miracles involving the child with DS. Her child was not developing and not reaching milestones, but as soon as she went to church, the child started reaching milestones including walking and talking. The child now sings with the church choir and loves being at church. The mother reported that as a single parent her own mother and siblings had turned their backs against her and rejected her child. She was in despair and had no one to turn to for support, but once she found God, everything changed in her life and she feels that she is on top of the situation and the clan has suddenly started following her. She is grateful to God for giving her an angel in her son with DS whom she says:

*“....opened up doors of hope for me.”*

The various ways in which African clans made sense of DS and the experience of raising a child with DS is consistent with the findings of an earlier study conducted by Ross (2008:18) on how African clans made sense of various serious medical diagnoses with the assistance of tradition and traditional healers. She found that several African traditional healers believed that cranio-facial conditions signify that the affected individual has been identified by the ancestors to become a traditional healer and that one should therefore not interfere with the ancestors' wishes through surgical intervention. She cautioned that this belief raises ethical concerns for social workers as on the one hand social workers are expected to respect the cultural beliefs of different groups; however, they also needed to consider the rights of affected individuals to receive surgical intervention that could potentially enhance their quality of life.

Another issue revealed in Ross's (2008:19) research which was also confirmed in this study was that many disorders and disabilities were perceived as a form of punishment for wrongdoings. Again she warned that such perceptions are likely to evoke intense feelings of guilt in parents, caregivers and affected individuals. Therefore, in her view the question that arose was whether social workers should simply encourage people to work through these feelings in counseling, or whether they have an ethical obligation to provide people with information on the "scientific" nature and etiology of the condition—information which could in fact run counter to their religious and cultural beliefs? Her personal stance was that it was possible to provide such information in such a way that one still conveys respect for the client's cultural beliefs and values.

The second coping approach is called emotions-focused coping. The emotions-focused coping centers on the appraisal of a stressful situation and the subsequent management of the outcome of such appraisal. The manner in which the African clan appraised the experience of raising a child with DS appears to have given the clan a perception of either severity or easiness of the perceived stressor associated with raising a child with DS. When this appraisal was made, pertinent emotional reactions were experienced by the clan. Depending on the severity of the experience as appraised by the clan, an emotional reaction was experienced and the clan attempted to cope with such emotional state. For instance, on the one hand, those that viewed it

as an indication of God taking them from one position to another remained calm and dealt directly with the experience with hope, as shown by the following statement:

*“We as a clan accepted the child as a gift from God. You know God always have a purpose and I can tell you his purpose is good. It may not seem like that now, but it will become obvious with time that he is lifting us up from one situation to another.”*

On the other hand, those who saw it as punishment for some misdeed experienced guilt and sadness and used various techniques of denial and avoidance while attempting to come to terms with the experience. This is expressed in the sentiments by one of the fathers below:

*“We are a clan of strong, fearless people. ‘Re ditau’ (we are lions). It can’t be that we have such a feeble child. That can’t be us. Watch the space; our ancestors are on our side. This child will grow strong and surprise many that are saying he will be mentally disabled and slow. Not ours. Our child will be just fine.”*

As discussed earlier, the solution-focused coping looks to changing or altering the environment in response to the stressor, whilst the emotions-focused coping involves efforts to regulate or manage stressful emotions by utilizing mechanisms that avoid direct contact with sources of stress (Gellis, 2002:39). These coping strategies are split up into two main groups: those that deploy attention away from or towards the stressor, and those that attempt to change the meaning of the transaction with the environment (Gellis, 2002:39) which will now be discussed.

A common theme emerging from the data was that most of the clans were secretive about their child with DS. The issues were kept secret and some households did not want neighbours and community members to know about the condition of the child. This might have been part of bargaining and depression stage in line with Kubler-Ross’s grieving process as outlined by Chapman (2013). Kubler-Ross emphasises that bargaining allows grieving individuals or clans to find something to hold on to such as faith in God and such a step culminates into depression which is associated with emotional reactions to the resultant settlement forming an outcome of bargaining. This

depressive episode is also known as preparatory grieving as it eventually leads to acceptance. When asked why this was so, one participant answered as follows:

*'ditaba tsa lapa di agelwa leshaka' (you build a kraal around affairs of the clan or clan affairs are ring-fenced).*

The participant explained that:

*"This is done for safety reasons as they do not know who their enemies are. The enemies can worsen the situation if they know all details about the nature of challenges confronting the clan and how the clan is handling the issues"*

The above may be viewed as an emotion-focused strategy that deploys attention away from the stressor. For some clans who may have not been ready to deal with the issue, it might have been easier to cover it up and avoid having to deal with it with others in the community, especially neighbors. These also include fear of the unknown about what potential enemies might do with the information about the condition of the child. The clan may not be ready to deal with such and perhaps if ready, the clan may necessarily be fearful.

Despite the concern expressed by clans about safety from enemies amongst their neighbours and community, most of them reported that they lived harmoniously with their neighbours. They expressed their appreciation for the warmth that the child with DS receives from the neighbourhood.

*"Everyone adores her",* one participant said.

*"They will not allow anyone in the neighbourhood to take advantage of her, they are very protective of her.... They want to help her... make things easy for her... when she comes back from school everyone wants to greet her."*

However, some clans expressed grave concerns about the bad treatment that the child with DS receives outside. One mother lamented:

*“ba tla tsoša sesho... bohloko bo o bo kweleng ge o botšwa gore ngwana ke segole...bona ba fihle ba mo hlorishe...ba mmitša ka maina a bohloko, ba re segafi... ba be ba rute le bana ba bona gore ba mo sege... o fihlele ba mo gobokanetše..” (‘the community make you relive the trauma you experienced when you were given bad news about your child’s condition. They bother the child...call him bad names. Some saying he is a lunatic...others even go to an extent of teaching their children to ill-treat my child...mock him and they will gather around him to provoke him’).*

Three households from Limpopo, Mpumalanga and North-West reported very tragic experiences of rape of their girl-children with DS. The three of them were raped by someone known to the household who lived in the community and knew the condition of the child. All cases were never prosecuted for lack of evidence as the child with DS could not express themselves clearly to give account of what happened. Consequently, the accused were released from prison leaving the clans of the victims agonised and aggrieved for lack of justice for their children. The rape occurs when parents are gone to work and children are left alone or in the care of siblings.

*“I was extremely hurt, and I sometimes blame my husband for not supporting me on this fight against the perpetrator. I have to go to work, sometimes miss work to go chasing the investigating officer. Eventually they say the case is dropped because there is no sufficient evidence. Simply because my child is not articulate and assertive to explain what happened the case has been closed without any investigations or prosecution, even though there are witnesses.”*

*“I feel angry at times I feel like going and strangle that boy with my own hands for what he did to my child. Unfortunately, she cannot speak for herself, but I found him on top of her and he ran away. Now the case is dropped and that hurt me as a mother.”*

*“I have left everything to God; he will deal with this boy who abused my daughter. The justice system failed me. It’s okay. I said God; the battle is not mine but yours. Deal with him.”*

Some clans reported that the most difficult thing about raising a child with DS is that you have to be with the child all the time or at least have a household member or kind

neighbour who can watch the child for you while you are away. This has been a difficult journey for most households given that some work and their other children go to school.

The clans expressed negative perceptions about institutionalisation. They wanted to live with their children and send them to a day school or day care centre. The mothers, in particular felt that their children with DS needed their care and would be in a better place to look after them than anyone else. They viewed institutionalisation and even boarding schools as inappropriate almost equating it to dumping or abandoning their beloved children. Some clans reported that they did try using boarding school, but after a while withdrew their children as they thought they were not being cared for in a satisfactory manner.

*“We sent our child to a special boarding school in Lebowakgomo (about 170 KM from home). The first few weeks were fine, but later on it became unbearable when we heard how badly the child was treated. We discovered that she was made to share a bed and share blankets which was never disclosed to us before and we were made to believe that she had her own bed and will use her own blankets. When the child visited for holidays, we decided she is not going back to that filthy place.”*

*“I know how to take care of my child. I know what works and what does not work and I love my child. Someone else is doing it for a salary and they do not have a heart for it. It pains me when I see my child being ill-treated when I am alive as the mother. So I decided, I would rather look after my own child than to dump my child with these people at the special school.”*

However, all of them reported that the child was well accepted and cared for within the family as confirmed by the following statement:

*“They all love him, the cousins and siblings and all relatives.”*

However, several of the mothers reported that they encountered challenges with their husbands or partners refusing to accept the child with DS. Some disputed paternity of the child with DS leading to them completely dissociating themselves while others

claimed that they have never had such in their clans and therefore it cannot be their child. This presented a double blow to the mothers as they had to deal with the fact that their child has DS and at the same time deal with rejection from the father of the child who rejected the child and eventually the mother as well. The mother had to deal with multiple losses of a normal child, loss of an opportunity to raise the child with a father as well as loss of a companion/partner/soul mate.

*“It was a double-blow for me and my household. While trying to come to terms with the loss of a normal child I was hoping for, I had to also deal with the loss of my husband that I shared life with for a long time. He deserted us and we now had to make ends meet on our own as a household.”*

The data showed evidence of emotion-focused coping strategies to turn attention away from the stressor. The literature indicates that “avoidant” coping is one of the strategies used under this broad category of coping mechanisms (Gellis, 2002:39). Avoidance is one of the most common forms of emotion-focused coping that turn attention away from the stressor according to Gellis (2002:39). Through avoidance, some African clans attempted to separate themselves from the source of the distress through being secretive about the condition of the child. Some participants and households sent their children away to special boarding schools. Some mothers and significant other clan members in the focus group reported that:

*“It was not easy for me; I tried to give away the child for adoption at one point, but later decided to just continue looking after my child.”*

*“We know of many other mothers and clans with children with DS who are not willing to come out and participate in support groups or even allow the community to see their children with DS... they are afraid of exposing themselves and do not want anyone outside to know about the child’s condition.”*

*“It pains me when people struggle with acceptance and end up resorting to being secretive. It is not in the best interest of the child or the household. We try to approach the mothers and advise them, but it takes time for them to come out and deal with the issues.”*

*“We are here to support each other; we cannot force anyone to come. Some take their time before they open up and want to engage with others and share their experiences. We try to reach out and provide the necessary support and information, but at the end it is the individual who decide when they are ready to engage with the support group.”*

It was evident from the data that some of the members of the clans and household members would hide their children with DS from the community.

*“I know of one parent who opted to give away the child for adoption. She wanted nothing to do with a child with disabilities.”*

While other clans with senior members available made sure that the senior members of the clan took the child from a younger mother to let the mother focus on her career while they took care of the child.

*“My daughter struggled to accept the child. As a clan we discussed the matter between the aunts and uncles and decided that I had to step in and take the child from her because we feared she might end up putting the child’s life in danger. So the child is under my care and the mother is in Johannesburg.”*

The above statements demonstrate the attempts by the clan or members of the clan to find ways of effectively reducing distressed emotions and improve their emotional state through adopting strategies that turn attention away from the stressor in confirmation of what has been stated by Kitaoka-Higashiguchi et al. (2003:42). Another sub-category of avoidant coping strategies is “escape-avoidance” (Folkman & Lazarus, 1991:210). By employing escape-avoidance, the clan attempts to escape from their stress through efforts such as wishful thinking, recreational drugs, medication, smoking and drinking. Although this form of coping may provide the individual with a short lived solution or respite from the stress, these tactics are often associated with ongoing anxiety or depression, and do not prove to be successful in the long run as argued by Tyson et al. (2002:456). Only one mother reported to have resorted to drinking alcohol while several of the parents resorted to wishful thinking, mainly motivated by spiritual or cultural beliefs that the child will change and become well.

*“I started drinking a lot and neglecting my child. I tried giving the child away for adoption, but it did not work. I had no one in my clan to assist me. It was difficult. Drinking alcohol became my way of escaping from the stress.”*

The data also showed strong evidence of emotion-focused coping where strategies that turn attention towards the stressor were used. This kind of coping mechanism comprises three types, viz., vigilance, distancing and positive appraisal as argued by Folkman and Lazarus (1991:217). Vigilance involves an attempt by the family to direct their attention towards the offending stressor in an attempt to prevent or control it (Folkman & Lazarus, 1991:210). Vigilance can include seeking help from others about the problem, as well as formulating a plan to deal with the problem. The data showed that some clans in this study applied vigilance. One common form of vigilance is their active participation in support groups as well as other advocacy engagements within and outside their communities. The participants reported consulting various social support structures within their clans including consulting with elders, traditional healers and religious interventions.

*“... sengwe le sengwe se tsamaya ka iketlo ka ngwana wa DS, ke tshwanetse ke tlhaloganye gore .... ke ngwana yo o sa itekanelang, ... ke nne ke reetsa bo sister ko kliniking kgotsa batsadi ba ba nang le bana ba ba bokowa” (... everything is slow with this child... I must understand because the child has a disability. I should also listen to advice from the nursing staff as well as other mothers who have children with the similar condition)*

The above reflects vigilance as the mother realised the difficulty associated with coming to terms with the fact that the child is slow in all milestones. She sought guidance and assistance from the nurses and fellow mothers in a similar situation and found it to be helpful. Thus, participation in a support group represents one form of vigilance. The one example of distancing is the verbatim cited earlier where the clan decided that it will be too overwhelming for a young mother to have to deal with raising a child with DS and rather opted for the grandmother to step in and take over caring for the child while the mother continues with her career in Johannesburg.

The participants were involved in one way or another with the treatment and care of their children with DS and were receiving some medical and therapeutic interventions which also reflect vigilance. There was also strong evidence of the clans' involvement in trying to find educational opportunities for their children. All of these have proven to be a positive coping method in the sense that it provided the African clan with a greater understanding of the stressor itself, and thus a greater sense of control over it. Vigilance can however, also have negative ramifications for the family as it may intensify the emotional distress related to the problem by elucidating the true severity of it for the challenge (Gueritault-Chalvin, Kalichman, Demi & Peterson, 2000:158). This has been attested to by the various feedbacks from family members pointing to the fact that raising a child with DS is immensely difficult and stressful despite all attempts to deal with it head-on.

*"It was very difficult, but we decided as a clan that we are going to deal with this directly. We never gave him away to special schools or shelters. We raised him on our own because we wanted to learn about the condition and we accepted the challenges and wanted to shoulder it. There is a saying in our language that says 'you can only tell the luggage is too heavy or light when carrying it on your shoulders', so we took on the challenge and indeed, it was tough, miserable and messy. It's not easy. It is frustrating and it even threatened the unity of the family, but we held on together."*

*"Why should we give our child away or consider abandoning her in some special school when we as parents are alive? We care for our children, with or without a disability. It is our duty to care for them. Another person will never care for your child the same way as you do. Some don't even understand the children. They are merely doing a job."*

*"Tlou ga e imelwe ke morwalo wa yone" (An elephant cannot be burdened by its own responsibility).*

*"God did this with a purpose. We cannot run away from it. Our ancestors are watching."*

*"It is our moral duty to look after our needy people, young and old, abled and disabled. We serve God by doing exactly that. If we don't, then God will punish us accordingly."*

Another coping mechanism of 'distancing' involves attempts by the person experiencing stress to acknowledge the stressful situation, but does not attempt to deal with its emotional significance (Gueritault-Chalvin et al., 2000:158). The data did not show any current form of distancing, except for the fact that some participants reported that they are aware of others who avoid contact with the support group and choose to remain isolated for a period of time, especially those with children who have been newly diagnosed. The participants reported that they resorted to distancing immediately after the diagnosis was disclosed and it allowed them to deal with the emotional reactions before they could start engaging with others in a similar situation. The anecdotal reports of some clans that lock up their children with DS also attest to this coping mechanism. This implies that the strategy worked for some particularly in times of severe emotional crisis.

While positive appraisal relates to the reframing of what might seem to be a difficult and bad experience in a positive manner that enables the individual or group to move forward positively (Gellis, 2002:47). This is very common amongst the African clans. The most common strategy being the tendency to view the difficult situation spiritually as representing God's will and purpose. One mother said:

*"I accepted the child as a blessing from God and gave him my best care. He is a lovely child and everyone around adores him. The community loves him so much and are very protective of him."*

In this category, all efforts are aimed at changing the meaning ascribed to the experience (Gellis, 2002:47).

*"When God gives you a gift, you accept it and do your best with it because you do not know where he is leading you."*

*"The child with DS has been the best thing in our lives. We all love him and the community loves him as well. They are very protective of him. No one touches this child, anyone comes to his defense."*

*“As a family, we were challenged at first, but he has since become the glue that brought us together. We do our best to care for him and we are grateful for the gift from God.”*

However, it would appear that the positive reappraisal was not merely a psychological configuration of a perception about the experience, but a deeply spiritual phenomenon. Most drew inspiration from their ancestral and religious belief systems. Whilst positive reappraisal can generate positive emotions such as satisfaction or pride, it can also reduce the negative effects of emotions such as fear, anger and sadness (Gellis, 2002:47). A good example is the appraisal of the birth of a child with DS as a wonderful gift from God which was a dominant and most common narrative.

*“We are grateful that as a family we have not given in to the temptations to give our child away to special schools, but we care for her on our own as would be expected by our ancestors. We have done all we could including the traditional ceremony for the ancestors ‘lesiko’ and we are confident that things will only get better.”*

*“We believe in God and our dealing with the child is inspired by his Word. We do not feel bad about the child, we do not blame anyone. We are grateful that God blessed us with this wonderful child and we are looking forward to his blessings as we move forward. He promises in his word never to forsake us.”*

It seems that, the use of the emotion-focused strategies in managing stress reactions amongst the African clan raising a child with DS yielded positive outcomes with some of them while it yielded negative outcomes with others. This is because some of the stress experienced associated with DS related anomalies such as the congenital abnormalities and malformations, slow development and the stigma and emotionally taxing effects of raising a child with DS are permanent stressors that are not likely to change over a brief period of time. Thus, coping strategies such as avoidance and distancing could have not been useful in dealing with these types of stress, as the existence of these stressors remains the same, and drawing attention away from them did not solve any problem.

However, other tactics such as vigilance provided the family with a better understanding of the said stressors, and possibly enabled them to form plans of action to begin managing them. This being said, certain stressors, such as the impact of a lack of experience raising children with DS on the part of the African family, might have been ameliorated by strategies such as avoidance and distancing, since a lack of experience is something that will inevitably change over time, as the family becomes accustomed to the DS condition, and in this instance these tactics can allow them room to cope and function more effectively as argued by Gueritault-Chalvin et al. (2000:151).

In conclusion, it has become clear in the discussion that clans will react differently to the birth of a child with DS leading to an experience of varying degrees of stress. Such stress reactions may be effectively contained or worsened depending on how they are appraised. The appraisal is dependent on the clan's capacity to deal with the demands of the stressful situation related to the birth of a child with DS. Better capacity leads to better coping whereas lack of capacity may lead to more overwhelming degrees of stress reactions. Sometimes, negative appraisal may be attributed to lack of information. Additionally, the use of Kübler-Ross's grieving process illuminated better understanding of the grieving process that the African clan goes through in their attempts to come to terms with the loss of an expected normal child. Therefore, the ability or capacity of the clan to access accurate information may hold the key to better coping. However, dealing with accurate information requires that one is emotionally stable to contain such information. Therefore, social support is important throughout in order to assist with appraisals, provide tangible support including both practical aid and provision of needed information. Having dealt with the stress reaction and the grieving process following the birth of a child with DS in an African clan, we will now analyze the nature of social work services in South Africa that are likely to assist the African families raising children with DS with psychosocial support.

### **Theme 3: The African clan's intersection with social work while raising the child with DS and their suggestions for improvement of social work services.**

The following section focuses on reflections by the African clan raising children with DS regarding their experiences with social work. The first part deals with the account of African clans regarding their experiences with social workers while raising children with

DS. This will be followed by their suggestions regarding the improvement of social work services to ensure that they are assisted in a culturally sensitive manner.

### **Sub-theme 3.1: Social work services received by clans raising a child with DS**

The data gathered showed that, although most public hospitals have social workers in their staff compliments, patients in need of social work intervention still go without receiving any assistance. The participants interviewed reported that they never received support from a social worker within the health care setting. The same situation seems to be the case in the communities where the DSD is the custodian of social work services. The participants interviewed reported that they did not receive any social work assistance in the community. Some participants who were assisted by social workers in the community seem to have been those households or clans whose children were victims of sexual offences (raped) and the intervention of social workers was in response to the rape incidence rather than the challenges accompanying DS condition. As a result there is no data relating to the nature of social work services offered to families raising children with DS in health care settings as well as community-based organisations. The area remains neglected by the social work profession in South Africa despite the huge impact it has on the psychosocial front as well as the fiscus due to its disabling nature. Below are some of the responses related to the lack of assistance from social workers:

*“We were provided with counselling by a nurse and doctor at the hospital. We never saw a social worker.”*

*“No social worker helped us in the community; we were only assisted by the DSA through the support group.”*

*“The only time we met a social worker was when our daughter was raped and the social worker came to interview us to compile a report, other than that, we never received any help from a social worker.”*

*“We do not know where to find a social worker in the community; we never received help from any social worker.”*

### **Sub-theme 3.2: How African clans would like to be assisted by social workers in a culturally congruent manner when raising their children with DS**

Although the African clans interviewed had not received any help from social workers, they were able to reflect on their expectations with regard to social work services. The African clans reported that they would like social workers to assist the clan to deal with stressful reactions to the experience of raising children with DS as shown by the following statements:

*“Sometimes the emotions are too overwhelming... any form of assistance from social workers with regard to dealing with difficult emotions would be helpful.”*

*“It is difficult to come to terms with having a child with DS. There is so much stigma in the community, social workers should assist us and also educate the community about the condition.”*

*“Social workers should be able to come to the clan and talk to the whole clan about DS. We understand that nurses and doctors can't do that, but at least social workers must be able to do home visits and talk to the rest of the clan.”*

The African clans did not use the word counselling, but instead used the word emotional support and advice. Various vernacular words were employed such as ‘thekgo ya semoya’, ‘nseketelo wa ximoya’, ‘ukududuzwa’, all of which imply emotional support. They also used the word ‘advice’ in their narrative. They expected social workers to provide advice on how to manage emotions emanating from raising a child with the DS condition.

The data showed that they prefer a more clan-centred social work intervention that is pitched at the level of the broader clan system. The clans also added that they struggled with accessing grants for their children. They would like social workers to play a more active role in this regard to ensure that the children that are needy and deserving are assisted quickly to access the grants.

*“We struggle so much with grants, sometimes we don’t even know what is needed to meet the criteria, but yet there are social workers, why can’t they come and help us with grants applications?”*

*“The social worker can assist with all of these things, the grant, special school and other issues related to the child’s well-being, but they are nowhere to be found.”*

*“Why should the child be raped first before they come? They should be able to assist us before our children end up victimized by rapists.”*

The above statements point to a number of issues surrounding social work including the fact that social work has not prioritized services to the African clans raising children with DS despite the debilitating conditions that the clans have to deal with. The reflections from the African clans point to one common theme that they represent a group of people that require psychosocial support at all levels of the continuum of care as outline in the FSWS (DSD, 2013:27). However, it is surprising that despite the evidence pointing to their need for services, they remain neglected. The statements also point to the fact that the public including African clans raising children with DS lacks understanding of the role of social work and its scope of practice. They seem to have constructed their views around what they have seen social workers do such as arranging grants and responding to crisis such as rape.

The African clans also added that they must be helped once clustered in the form of support groups to develop personal and organizational capacity to formalize their work through building sustainable organizations that are well-resourced to tackle all challenges related to raising children with DS at their local community level.

*“We would like to register as an organization, but there is no one to help us. Social workers from the DSD should have the information we need.”*

*“...there is even more people out there with children with DS, who are afraid to come out and participate in the support group. If social workers were more involved, we could*

*be assisted to raise awareness and create a safe environment for these people to come out.”*

The African clans reported that they would like social workers to help them secure land and funding for their organisations to operate from, as well as ensure that they guide the process. They also expressed their desire for the social workers to ensure that special schools are built locally so that their children can attend daily from home and not have to be sent far away to a boarding school. The African clans expressed their distaste of distant boarding schools because of their mistrust for such schools. They reported that it is emotionally difficult for them to have to accept that their children with disabilities are taken away to a far place where there are always possibilities of them being ill-treated. They expressed a desire to raise their children on their own at home and for the special schools to be available as day schools so that their children can attend during the day and come back home after school.

*“Tlou ga e imelwe ke morwalo wa yona. Le ge go le boima, re tla itshoka ra tswela pele ka botshelo le ngwana wa rona wa bokoa. Re ka se molahle, re a mo rata, re a mo amohela”* (An elephant cannot be burdened by its own responsibilities. Although it is difficult, we will forge forward and look after our child with DS. We will not throw the child away. We love and accept the child)

*“It is so painful to imagine what might be happening to your child when he/she is at a special school far from home. Some people, especially those that do not have children with disabilities do not know how to handle our children and they end up abusing them.”*

*“Modimo a ka se go fe morwalo wa palelwa ke go o rwala. Le ge go le boima, ke morwalo wa rena re tla katana le wona. Ge ele go lahla ngwana di boarding school rena re ka se kgone. Ngwana a ye a sokole, a hlakišwe ke batho ba ba sa tsebeng le bohloko bja go belega... Modimo o tla re thuša ra ikgodisetša yena”* (God will not give you a challenge heavier for you to carry. Even if it is difficult, it is our burden, we will grapple with it until we can manage. As for dumping our child at a boarding school, that we will never do. Children suffer there in the hands of people who do not even know the pain of giving birth to a child... God will help us raise our child).

The above sentiments imply that it is a divine responsibility of parents not institutions to look after children. This observation has often been met with critique, as in the case where Ryke, Ngiba and Strydom (2003:139) point out that “traditional cultural practices of black African people to keep their elderly persons with them remain a stumbling block to getting them to utilise the provision of institutional care by the government”. It was found that black people prefer utilising their extended family systems instead of institutional care on the basis of their belief of “not throwing away” their people (Ryke et al., 2003:139). In other words, the elderly and by extension, children cannot be regarded as burdens for parents. This conviction provides positive reinforcement in helping mothers to accept and cope with their children with DS. From the point of view of the strengths perspective, this points to an important social asset that needs to be harnessed.

Furthermore, the quest for clan-focused interventions is another indication that the African family functions in a collective and communalist manner contrary to the western individualistic approach. This implies that the clans learn, grow and develop collectively as advanced by the social constructionist perspective. Therefore, any kind of intervention for social support should build on this inherent strength and existential condition and reality of the African clan system.

Furthermore, the clans seemed to be having an understanding of, and also accepting community-based stigmatizations and stereotypes around DS. They also felt that the social workers could intervene to address these at community level. However, they expressed greater aggravation and expressed disappointment at misconceptions and labelling coming from inside the clan and households, which sometimes if not properly modified and contained, may lead to a complete disintegration of the clan system. This again added to their call for clan-focused interventions. The data was unequivocal when it comes to defining who they referred to as the clan. The fact that it was not just a conjugal pair, but a broader network of people within the kinship related by blood came out clear from the data. In relation to this, Van Der Walt (1990:37) stressed that “the spirit of communalism is inherent in traditional African cultures as opposed to the western cultural emphasis on individualism.” Furthermore, traditional African communities view duties towards the community as paramount, hence the belief that

“all children in the community are children of all adults in the community- ‘my child is your child’” (Van Der Walt, 1990:37). The researcher is of the view that the above findings provide opportunities and strengths for sustaining change efforts and should be encouraged in an effort to provide social work services that are responsive to the actual needs of African clans raising children with DS. The participants expressed their appreciation of an opportunity to belong to a support group and efforts of the multi-disciplinary team that assisted them on an on-going basis. They all stressed that the support group itself assists them to deal effectively with challenges they encounter in their lives.

A deeper analysis of the data reveals that on the whole, Africans use formal services as an alternative to the network of traditional support systems they deploy as a first choice. It appeared that the African clan relies on a myriad of traditional and culturally significant support systems including relatives, spiritual leaders as well as elders. Again these are all assets that need to be developed and capacitated to ensure that they are able to continue to provide the much needed help. Additionally, it can also be deduced that Africans have traditional beliefs about the causation of problems (such as the belief in witchcraft) and beliefs about remedies. These should not be viewed skeptically, but fully acknowledged as sources of strength and properly harnessed to yield good results associated with congruence. When the clans receive assistance that embrace their belief system, seen through their eyes and lenses, the intervention outcomes are more likely to be sustained, while growth becomes more organic than superficial. The clans will grow and change on their own when they find evidence-based grounds for change rather than such being imposed on them by an external agent that they may resist. This is part of their existential condition (lived experiences) and it would not help to dismiss them as less important. They are in fact as important as any other aspect. Accordingly, social workers should encourage the acceptance and embrace these traditional beliefs.

**Theme 4: The social workers’ opinions regarding the level of congruence between the services they render and the cultural orientation of the African clans raising children with DS, culminating into their suggestions for improvement of social work services.**

The following section deals with the opinions of social workers regarding the level of congruence between social work services and the cultural orientation of the clients when rendering social work services to African clans raising children with DS. The above theme is covered through a discussion of three sub-themes. The first sub-theme deals with the social workers' reflections on their actual experience working with African clans. The nature of social work services rendered by social workers in health care settings and social workers in welfare services is discussed. As indicated earlier, there are two categories of social workers involved in this study; that is social workers employed by the DoH located mainly in but not limited to hospitals and referred to as social workers in health care and social workers employed by the DSD known as social workers in welfare services. The second sub-theme deals with social workers' views and reflections on managing the incongruences between social work and the cultural orientation of African clans. For social workers who might have not experienced this, they were asked to share their views on how they would consider managing such disparities should they arise in future in the course of their work; while the third sub-theme deals with the social workers' suggestions for improvement of social work services to African clans raising children with DS in order to make the services more culturally responsive and relevant.

**Table 6. Demographic information on social workers**

<b>Category</b>	<b>Description</b>	<b>Number of participants</b>
Gender	Male	5
	Female	15
Employer organization	Health setting/Hospital	6
	DSD/Welfare services	14
Highest qualification	Bachelors degree	18
	Post-graduate qualification	2
Work experience	1-5 years	11
	6-10 years	6
	11 and more years	3
Total		20

The demographic information of the twenty (20) social workers interviewed in this study provide a breakdown of information about the gender, 'race', employer organization, years of experience and their highest qualifications. With regard to gender distribution, fifteen (15) out of the twenty (20) social workers interviewed were female while only five (5) were male. The fact that the participants were selected on the basis of their availability confirms the findings of an earlier study conducted by Earle which found that 89.3% of registered workers were female (Earle, 2008:46). The findings clearly depict social work as a highly female dominated profession in South Africa, which is also confirmed by the report on the review of the White Paper on Social Welfare (DSD, 2016:263). This trend is reinforced by dominant cultural values, norms and perceptions that assign nurturing and caring roles to women. As explained by the social constructionist/constructivist theory, the society transmits the messages from one generation to another and when people internalize such messages at personal (constructivist) and collective (constructionist) levels it automatically translate into the trends observed in this regard where certain professions remain dominated by a particular gender. In this case, more women find it preferable to take up social work as a profession than men.

As indicated earlier, social workers interviewed came from health care settings (hospitals) and welfare services under the DSD service points in the four provinces that formed part of this study. As indicated by the DSD's (2016:236) report on the review of the White Paper on Social Welfare, "... within the provinces, the vast majority of social workers are employed by the departments of social development and welfare, while the departments of health employ the largest portion of the balance". Fourteen (14) social workers came from the DSD with most of them coming from the two North-West DSD service points in Potchefstroom and Mafikeng. This was purely based on convenience and accessibility made possible by the management of the two service points in the North-West province who actively ensured that social workers are given time out to participate in the study and interview venues were also allocated for this purpose. This was unlike in other provinces where management was not so keen and open to giving the researcher access to their social workers. Only a small number of six (6) social workers had more than six (6) years' work experience whilst eleven (11) had between one and five years' experience practicing social work. Only two (2) had postgraduate qualifications while the rest had a bachelor's degree. The fact that all social workers

had more than one year work experience, meant that they have had adequate time in the field to be able to share meaningful experiences rather than someone without experience. The longer the work experience of the social worker interviewed implies that the information they provide would be more meaningful and richer. Furthermore, the level of education also influences the quality of data. For instance, the two social workers with postgraduate qualifications had an advanced understanding of work in a particular area of work that they studied at postgraduate level, which may not necessarily be the case with social workers who obtained only a bachelor's degree. Thus with postgraduate qualifications comes quality and a richer account of phenomena in the interviews. However, Earle (2008:15) notes that very few social workers consider postgraduate studies in social work. Notably, those that choose to study further often opt to follow other cognate disciplines such as psychology, sociology and criminology/law other than social work (Earle, 2008:15). This trend may impact negatively on the social work profession as it constitutes a brain drain that weakens the profession. This weakness may emanate from the fact that as a consequence of the brain drain, a higher percentage of the pool of available social workers practicing are likely to be without postgraduate education and therefore without advanced and specialized knowledge and skills that are so required to meet the specialized needs of their clientele. This may consequently have adverse implications for the quality of service and the general reputation of the social work profession.

Sub-theme 4.1: Social workers' experience working with African clans with regard to services rendered and the reception of such services.

The interviews with social workers included social workers in health-care settings (hospitals) employed by the DoH as well as social workers employed by the DSD to render welfare services in communities as already indicated earlier on. On the one hand, almost all except one social worker practicing in a health care setting reported that they had never worked directly with African clans raising children with DS. However, even though most of them did not work with African clans raising a child with DS, the social workers reported that they work predominately with African clans and were able to share their experiences in this regard. The one social worker in this category that dealt with a couple with a child with DS, gave detailed account of her

experience with the African clan raising a child with DS. She considered this social work with a family. She reported that her intervention was short-lived as the child had to be discharged.

*“I saw the parents with the child for only two sessions and had to terminate because the child was discharged.”*

The social worker reported that she did not notice any problem with the manner in which she interacted with the couple and that they were receptive of her intervention.

*“I used my professional skills and techniques when communicating with them and it all worked well and I thought they also followed the whole process with ease. They were quiet happy with my intervention because I spoke to them in Setswana.”*

The social worker above used an African language in her conversations with the couple and focused on helping them come to terms with the experience of giving birth to a child with DS. The social worker used her skills and techniques and no cultural issues were covered in the discussion. The social worker feels that the intervention achieved its objectives and the couple was receptive. The above assertions by the social worker that her intervention focussed purely on the objective of helping the couple come to terms with the bad news and that cultural issues were not covered confirms what Brydon (2011:160) cautioned the social work fraternity about: there is nothing devoid of culture in social work, the question is whose culture are you advancing? Similarly, in this case, the social worker does not realise that the very approach that she uses is cultural. Additionally, culture does not only define how people do things, but also how they view the world (Marais & Marias, 2007:813; Laungani, 2004:35). As a result Marais and Marias (2007:813) argue that a need exists for social workers to seek a deeper analysis of the implications of culture for humans and how they view the world. Meaning that social workers need to constantly seek to understand and see things from the view point of clients which implies seeing from the clients' cultural view.

On the other hand, building on the African worldview, the African existential philosophy is instructive: the existential conditions of the black subjects in an anti-black world

should be engaged from the '*ontological zero point*' which means that they should be understood from their lived experiences and their form of living that is reduced to non-existence (lack of ontological density), but possessing the ability to emerge (Sithole, 2016b:182). This means that African scholars should engage Africans from an understanding of their positionality which is unknown and undocumented. Because nothing is known of the reality of Africans, meaningful engagements with them should become tailored to co-construct so that eventually a new body of knowledge emanating from a collection of the various accounts of their lived experiences is developed. It is inescapable that failure to engage Africans from an '*ontological zero point*' will effectively lead to subjection. According to Sithole (2016b:179) subjection denotes the location and incarceration of black subjects in the positionality of the '*other*'. He maintains that in this positionality, black subjects are placed in the exterior to the zone of life and they are effectively condemned to a 'zone of non-being'. A similar determination was made by Biko (1978/2004:102) and Fanon (1952/2008:82) earlier when they argued that colonial deception has and still is subjecting black subjects on the long dogmatic sleep of subjection whose main object is to produce black subjects who are ontologically void.

It is noted that the social worker in this case, simply followed the known process of helping without consideration for the extent to which it falls into synergy or fails to talk to the existential reality of the client. As she explains:

*"I did my assessment at the beginning to establish what the issues were and they both verbalised their difficulty coming to terms with the bad news about their child with DS. We contracted on the goal of helping them explore ways of coming to terms with the situation and we worked on that goal which I believe at the end of my intervention, though short-lived, they made some considerable progress towards achieving the goal. We explored their fears and ways of overcoming them. We never dealt with cultural issues, we focused on the goal and we were able to achieve some progress."*

The above represents a typical blind spot on the part of social workers and their gullibility in their application of western social work theory when working with African clans. The social worker does what she believes to be correct within the available time frame and evaluates her tasks. One can clearly see that there is nothing about the

client in the whole intervention. Everything was about the social worker and what she needed to do. This is despite the proverbial claim of the principle of client self-determination in social work. There is no clear indication that the social worker allowed the couple to direct the process, determine the agenda for the intervention and the issues that should be covered. The researcher maintains that unless social workers make a conscious shift from technical rationality (a central feature of the Eurocentric paradigm) to embrace the idea of participating consciousness (prevalent in the African worldview where the helper and helped enter into a genuine, mutual interaction), social work will not succeed in achieving cultural relevance. An analysis of the statements by social workers from the African existential philosophy as a philosophical lens coupled with an appreciation of the African worldview in this case would highlight the importance of the lived experiences of the client as a starting point for the social work intervention. Meaning that when a social worker attempts to assist an African clan to come to terms with the bad news related to the diagnosis of their child with DS, the social worker would have to allow the clan to share their experience of what it means for them to have a child diagnosed with DS and how do they manage it. From this, the unique influence of the African worldview will be uncovered. Most importantly, the social worker joins in with the African clan in a mutual working relationship where both the helper and the helped learn and grow. This is contrary to the Eurocentric view that positions the social worker as a helper intervening to help the client. In the case of Eurocentric social work, the helper may easily continue to impose alien Eurocentric ways on African clans who are not in a position to even challenge the imposition because of the systemic, systematic, structural and institutional anchors that naturalises and canonise Eurocentric hegemony over other worldviews.

It is interesting to note the responses of participants (social workers) in the study when asked about their experience of working with African clients around cultural issues. They mentioned that they did not normally cover cultural issues when working with African clients as their focus is on the helping process and the best interests of the client at the time. Meaning that the silence on cultural issues is based on the belief that cultural issues are not linked to the wellbeing of the client.

*"I understand my role as being to provide professional assistance to the client on whatever psychosocial challenge they are facing. That is my focus, cultural issues are*

*problematic and I try to avoid going there because some client end up engaging in dangerous cultural practices that may be harmful to their health and the treatment they receive from the hospital. For example, they may want to stop adhering to the treatment regime and opt for 'muti'. I cannot allow that because it is not in the interest of the client and their health. I have a professional responsibility to confront them if they bring that and educate them of the dangers so that they may adhere to the medical treatment without defaulting"*

*"I do not want to touch on cultural issues because there is so much cultural diversity and most cultural practices conflict with medical treatment. I would rather focus on what I know is best for the client in line with what the multi-disciplinary team do"*

*"I believe that we have an ethical obligation to educate and empower our clients with information so that they do not engage in harmful practices. I will not initiate a discussion on cultural issues, but if it comes up, I will then play an educational role so that the client is empowered with information to understand what aspect of their culture is safe and what is not"*

However, contrary to the above assertions, when asked about a need for social work interventions that are culturally congruent and how that can be achieved, the participants saw a need for all social workers especially for non-African social workers rendering services to Africans to learn about the African cultural orientation and worldview. They emphasised the need to be sensitive to the cultural orientation of African clients.

*"We all need to be aware of the diversity of cultures and be sensitive"*

*"Its easier for African social workers to work with African clients because we understand the culture, I would strongly recommend that social workers who are not African be taught and exposed to the African culture so that they know what they are dealing with and be able to guide clients accordingly"*

*“we need to understand when our clients talk about ‘amadlozi’ so that we can educate them about the medical conditions and show the importance of taking treatment first so that the patient’s life can be saved”*

The above responses reflect the silencing power of social work interventions on African ways of being and knowing and the affirmation of a Eurocentric worldview as superior to the rest. This call to mind Brydon’s (2011:150) argument that any way of addressing human needs including all the approaches or techniques used in social work are cultural—the question is whose culture are they? However, due to the institutionalisation and systemic influence of colonisation and internalisation of coloniality, social workers may not realise that they are advancing the Eurocentric cultural hegemony in the course of their intervention. In some of the verbatim account provided, they may even feel that they are doing what is in the best interest of the client.

The other social workers reflected on their work with African clans generally as follows:

*“I find it easy to work with Africans because I am one of them. I know what is expected and treat them in accordance with their expectations. For example, if I am talking to someone elderly, I give them the respect they expect by not calling them with their first names, but rather using their surnames and titles such as Mama Sithole or Ntate Sithole. When I talk to a client of my age, I can use their first name. I also avoid eye contact when talking to elders.”*

*“I found that in most cases when I talk to Africans, I become very informal and relate to them at their level as elders.”*

*“I do not see any difference whether African or not. I develop a formal working relationship and keep it formal. I do not entertain cultural issues because I am not an expert on cultural issues and I do not want to discuss something I do not know and understand. The cultures are different and complex. Rather stay away from such complications and focus on what I know... what I was trained on as a social worker.”*

The above statements reflect a general lack of social responsibility and ethical consciousness amongst the social workers. By social responsibility and ethical consciousness, the researcher refers to the ability of the social worker to go beyond the professional call of duty to embrace his/her responsibility to make a difference in the lives of the clients in the most ethical way possible. Several social work scholars in South Africa cautioned that the social challenges facing South Africa call for the production of social workers who not only have globally competent knowledge and skills, but are also socially responsible and conscious of their role in contributing to the national development effort and social transformation (Earl, 2008b:3; Smith, 2008:374; Sewpaul & Holscher, 2004:39).

The social workers interviewed within the health care settings came from eight hospitals across the four provinces with three (3) hospitals found in Gauteng. Of the eight hospitals, all three hospitals in Gauteng had DS support groups initiated and housed within the hospital. Of the three hospitals in Gauteng running DS support groups, only one had social workers actively involved in the running and coordinating of the support group although it was agreed in principle that social workers as well as other allied health professionals within the hospitals needed to be involved.

The social workers from the two hospitals in Gauteng that were not participating in the activities of the DS support group reported that they were still working on preparations for their involvement and that they will be taking an active part in the support group. It appears that the DS support group so far is the only platform available for social workers to interact directly with families of children with DS within the hospital/health care setting given that the only social worker who reported direct contact with a child with DS and significant others came through her facilitation and coordination of the DS support group. This is because in that particular hospital, the role of facilitation and coordination of the DS support group is rotated on a monthly basis amongst members of the multi-disciplinary team, and the allied health professions in particular.

*“We have a strong multi-disciplinary team in the hospital and we rotate the responsibility of facilitating the DS support group, this is how I got to deal with a case of a family of a child with DS.”*

The social workers interviewed within the health care setting reported that they work mainly with Africans.

*“Our clients are mainly Africans. We provide psychosocial support to the patient and their family if necessary.”*

*“We do not have a standardised way of helping, we are quite flexible and it all depends on how much time the client has in hospital. We provide mainly short-term counselling because of time limitations. We are forced to do short-term counselling because patients are in hospital for a very short time. So we mainly focus on helping them come to terms with their medical condition or diagnosis particularly when a life-changing diagnosis (cancer, HIV/AIDS) or serious surgery (amputation) is made”*

The above statements imply that social workers are not guided by their professional norms, standards, scope of practice and knowledge-base when rendering services at the health care setting. Instead they are dictated upon by circumstances outside their professional obligations, including decisions by other professionals. This has been confirmed by Zastrow (2004:527) when he stated that practicing social work in a host setting is accompanied by challenges. This reduces social work to a quasi-profession status incapable of standing on its own right. Consequently, the social workers are not able to assess the needs of clients (African clans) and intervene accordingly to address the identified needs in a manner that is culturally relevant despite the fact that this is a key determinant for any meaningful and effective helping process. The social workers simply run-through an established process when convenient, in a one-size-fits-all approach. This is helping to meet the needs of the helper rather than helping to meet the felt needs of the helped; in other words, helping for the helper than for the helped. It is situations such as the above that led Smith (2008:374) to argue that “...unless there is critical engagement with the stark past and present realities of structural and social relations of power, privilege, inequality and oppression, social workers in South Africa will deserve the past label of being upholders of the status quo”.

It appears that there is no established protocol or guidelines for their work with African clans raising children with DS within the hospital environment. Their professional interventions focus mainly on counselling with individuals and/or groups of patients

admitted to the hospital and sometimes where necessary and compelling, they would involve a significant other in the counselling process.

*“If we involve a ‘significant other’ it is most likely to be a spouse, dependent/s or a biological parent or legal guardian of the patient.”*

When asked under what kind of circumstances would they involve the clan or members of the clan, the social workers reported that the involvement of the clan may be initiated by the significant other of the patient such as spouse or parent, if they are worried about the patient or some aspect of the treatment and management of the condition of the patient or may be invited by the social worker to join in one of the counselling sessions as confirmed by the following statement.

*“Some of the common reasons for inviting family members are: on-going assessment of the social environment of the patient/client, attempts to seek consent for certain treatment procedures when the patient is a minor or medically or psychologically compromised to give consent, disclosure of bad news (medical diagnosis), on-going feedback on medical information to significant family members as well as part of the routine discharge planning arrangements.”*

The social workers within health care settings were categorical, as reflected in their verbatim accounts wherein they state that they mainly do case work and seldom do group work. None of the social workers interviewed were running groups at the time of the study.

*“It is difficult to even do proper case work. We mainly do brief and short-term/crisis interventions. Doing group work and community work is almost impossible. I do not do group work and I am not aware of anyone running groups in this hospital and other hospital adjacent to us. Something needs to change in the broader approach to social work in health care settings to allow for more autonomy for social workers to do a proper job in line with their knowledge and expertise. Then we will be able to work on different strategies for addressing our clients’ needs including African clans. For now, it will be almost impossible because there is no space for doing anything differently. We*

*are trapped in a rigid system that denies us the space to practice what we were taught.”*

The above sentiments expressed by social workers in health care settings highlight a serious challenge of lack of adequate resources and unbearable workload as major reasons for social workers' inability to practice social work fully. Consequently, they have to cut corners. If left unchanged the above situation will make it impossible for social workers to implement the Afrocentric social work practice guidelines for assisting African clans raising children with DS. This is because the guidelines require that adequate time and staff be supplied as well as proper organisational environment that is supportive and accommodative of the African worldview. The reflections on practice by social workers in health care settings confirm the issues raised in the literature that the cultural heritage of Africans has not been used as a theoretical base to develop social work practice models. The Eurocentric oriented practice-based models remain at the centre of interventions used when assisting African clans resulting in the apparent lack of cultural relevance.

Social workers reported that they work under extreme pressure due to lack of resources required to perform their duties in line with the basic processes, standards, norms, values and principles of social work. They attributed this to the fact that the health care setting like a hospital is not a primary social work setting.

*“We are operating in a host-setting; the health care setting is not designed for social work. We are short-staffed and always under pressure. The workload is unbearable. Imagine having to service several wards alone. At the end you have to take a compromised position and only attend to urgent cases.”*

*“We have to fit in with organisational arrangements that are not adequately accommodating of our ways of doing things. Sometimes other role players like doctors don't even want to understand our approach, they instead impose on us what we should do and how long.”*

*“Our constant source of frustration is that our professional interventions are looked down upon and not viewed in high regard in comparison to other allied health professionals in the multi-disciplinary team.”*

Based on the above statements from social workers one deduces that, they are not able to negotiate rules of engagement that are favourable and accommodative to their professional standards and norms. Instead they have to compromise all those in order to fit in. This effectively erodes their professional standing and reduces them to mere appendices on the margins as confirmed by the statement below.

*“We end up operating at the same level as lay counsellors who have no professional standing with a defined scope of practice as well as norms and standards.”*

Social workers reported that there is a general lack of resources that are critical for effective and efficient social work service delivery. They reported that amongst important resources needed to enable them to carry out a professional social work service would be human, financial and material resources.

*“We are always under-staffed with some hospitals only having 1 or two social workers.”*

*“We are housed in normal office as administrative officials without consideration for the nature of work we perform which requires that we have therapy rooms for different kinds of therapy sessions and different kinds of clients.”*

As argued by Zastrow (2004:527) the health care setting as a secondary setting for social work implies that some compromises have to be made in adapting practice modes and conditions to the context which was inherently designed for health care services, not social work. The above verbatim accounts attest to the argument advanced by Zastrow. The data reveals a clearly confused expectation of the role of the social worker. Lastly, the social workers reported that they are not allocated an adequate budget to fund consumables and actual activities of social work. These may include telephone communication to link up with clients and their families, transport for home visits, money for programme activities and other essential resources required to carry out a comprehensive social work programme at different levels.

Asked about their general experiences of working with African families, social workers within the health care settings reported that they rarely work with the family (western) as their intervention is always aimed at providing psychosocial support to the patient and significant others who come to the hospital which in most cases will be a spouse in case of couples or a child or parent of a patient. When asked to elaborate who they consider family, they had this to say:

*“Husband and wife as well as their children.”*

Most of the hospital social workers reported that they believe their intervention is relevant and appropriate. They did not see a need to do things differently. They did not see the relevance of cultural and spiritual issues to social work intervention in health care. Rather, they preferred to focus on objective issues related to helping clients with certain problems linked to their presenting medical problem. When cultural issues came up which most of them reported that they do come up especially in relation to treatment options, they said;

*“One has to always focus on the best interest of the client.”*

*“I will give an instance, when a patient is diagnosed with schizophrenia and African families purport that it is spiritual, the social worker would focus on ensuring that the patient accepts and adheres to hospital treatment while respecting their views and never judging them.”*

The above verbatim response on the best interest of the client implies that cultural issues may not form part of the best interest of the client and that there are known best interests of the client. This is a reflection of the hegemony of the Eurocentric paradigm and a way of discounting other paradigms as less important. Unfortunately, due to the limitations of disciplinary decadence (narrow focus on disciplinary boundaries) which coloniality uses as a tool to perpetuate itself, the training of social workers in South Africa is not open and broad enough to expose social workers to some of the critical areas of self-knowledge including history, politics and African anthropology to develop critical consciousness. As Smith (2008:374) argues, social work needs to refocus on

structural change and social justice. Smith (2008:374) further stresses that "...a unique set of internalised and structural oppression of class, race and gender characterising post-colonial contexts calls for 'critical conscientization'; engagement with oppression and issues of power; a commitment to radical transformation; changes in epistemologies and efforts to change material conditions". She further proposed that radical and critical forms of social work practice based on a combination of a structural, modernist analysis as well as post-modernist critical theory must form the basis of social work training.

However, some of the social workers expressed that they would rather handle things with an open mind as they navigate through conflictual cultural and professional assessment of problems. They argued that experience has taught them a lesson as follows:

*"Some of these belief systems hold truth. I have seen people overcome certain challenges through interventions that are cultural and spiritual when modern scientific interventions had failed."*

The social workers in health care settings believed that there is lack of fit between social work and African culture. They saw social work as applicable and adjustable to all cultures.

*"Social work is adaptable, we just need to be open-minded and suspend judgement."*

The data coming out of interviews conducted with social workers seems to suggest that the focus of the social workers is limited to their direct client who is the patient and rarely involve the significant others.

*"We normally work with the patient as our primary client; seldom involve any other family members. This is because of lack of time and sometimes due to lack of resources given that the only way to see family members is when they came to visit their patient at the hospital. There are no resources for the social worker to do family visits."*

Contrary to Zastrow's (2004:527) assertion that social workers in health care settings may practice a broad spectrum of social work services ranging from case, group and community work, the data shows that social workers interviewed mainly focused on casework. It is noteworthy that Patel et al. (2012:215) stressed that the developmental social work approach in South Africa favors a generalist social work practice that is family/household-centred and community based; but the findings of this study suggest otherwise as there is no clear indication of a family/household-centred interventions and community work. Thus, the question is whether the shift to developmental social work had been successful or not, particularly in the field of practice. Its successful implementation in practice would mean that the African clans raising children with DS would receive social work services focusing on empowerment; that are non-remedial in nature; interventions that are concerned with participation and people's networks; as well as interventions that are concerned with economic development and independence.

*"I only do casework. The other methods such as group and community work are almost impossible to do due to a number of reasons. Firstly, the hospital environment is not conducive for group work because patients are sick and sometimes they are not able to move around to attend group sessions, there are a whole lot of security risks involved, there are no venues tailor made for group sessions and patients get discharged on a daily basis. On the other hand, there are no resources allocated for community work, so it is a no-no!"*

There was no attempt at practicing community work despite the need imposed by conditions such as DS. It is thus fitting that Zastrow (2004:60) rightfully acknowledges the World Health Organisation (WHO)'s definition of health as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity". The Social Model (also known as the Holistic Model of health-care) enables social workers to attend to the health needs of individuals, as described by the WHO. However, it must be noted that Zastrow's (2004:60) analysis and assertion of a holistic view of a patient as social work client, falls short of acknowledging other equally important aspects of spirituality and affect as propounded by the African worldview and cultural thought as argued by Ani (1994:43); Schiele (1997:803) and Brydon (2011:159) respectively. The findings of this study revealed that social workers in

health care settings are not practicing as per the professional norms and standards, but merely trying to fit in with the dictates of the host-setting and expectations of other professions. Therefore, the holistic model seems to find no expression in the manner in which social workers conduct their work in health care settings despite it being widely accepted across different professions and it being the basis for the conceptualization of the multi-disciplinary team common in health care settings. The above calls for a serious revitalization of social work practice starting from the training of social workers.

Furthermore, in order to make sense of the role of the social worker in health care settings, an analysis of such roles was done in line with the knowledge and theoretical base of social work as presented in the literature. Social workers interviewed in health care settings confirmed that they attend to the general psychosocial needs of clients.

*“We assist clients who are hospital patients with psychosocial support. This may relate to the condition that brought them to hospital or may be related to client’s family or work environment that influences their health condition.”*

*“We also address challenges that emerge out of the medical treatment plan which may relate to the need for surgery or amputations or any other major medical intervention with long-term implications as well as issues arising out of a diagnosis.”*

*“We assist the client come to terms with everything done at the hospital and its implications; this may be through giving information or educating the client or through some therapeutic intervention.”*

The above verbatim accounts are consistent with the role of social work in health care settings that is documented in the literature as including, amongst others, soothing patients' anxiety about hospital admission, circumstances at home, forthcoming surgery or treatment and future prognosis (Zastrow, 2004:285). Additionally, Cummins et al. (2006:4) theorize that the data confirmed the use of therapeutic skills, as well as the use of educational and task-oriented interventions in professional interventions of social work in health care settings.

Most importantly, as indicated by Zastrow (2004:285), social work services in health care are done in consultation with other members of the multi-disciplinary team (for input or referrals), and is directed towards both patients and family members. This was confirmed by the information shared by the participants.

*“We work within a multi-disciplinary team of medical staff as well as allied health professionals.”*

The data further showed that social workers in health care settings function within a multi-disciplinary team, but their role within the team seems to be weakened by the fact that they are looked down upon and occupy an inferior position.

*“We are not taken seriously and patients are often dumped on us for everything and anything. It seems other members of the team do not have a clear understanding of our role as their fellow team members. They know what to refer to a physiotherapist and what goes to a radiologist, but with us it is everything and anything that cannot be referred anywhere else.”*

*“We get referrals for patients who do not have ID books, unknown, transport money etc. What does that have to do with social work?”*

The above statements points to some possible weaknesses in the current practice of social work in health care settings with regard to multi-disciplinary collaboration as well as how patients are served. As shown in the data, only one hospital in Gauteng was reported to have social work actively involved in the multi-disciplinary team arrangements for children with DS and their families whereas all participants in rural hospitals were silent on this important matter. Furthermore, there was no data pointing to a strong component of work with families in relation to social work in health care. Instead, the data pointed to a social work service solely aimed at patients as clients, with occasionally consultation with a significant other when circumstances compel that this be done.

Furthermore, the fact that there is currently no specialization in health care in South Africa implies that those practicing in health care would be trained as generic social

workers without any post-graduate qualification. This is apparent in the demographic data of social workers interviewed in this study. The social workers interviewed had no postgraduate qualifications. This means that they will not be as professionally knowledgeable and skilled, with a negative impact on their confidence, as their counterparts might have been licensed for a specialization with a postgraduate degree as done in other parts of the world, specifically in the USA. This may also adversely affect their ability to negotiate terms of service so that they may set standards and norms for their rendering of services in a multi-disciplinary setting. The data suggest that social workers simply adapt to the demands of the practice context, which results in different arrangements in different settings within the healthcare field.

Finally, it appears from the data that social workers in health-care settings have not critically engaged any of the theoretical constructs defining their roles to respond directly to the needs and aspirations of a unique African clientele. As a result, they continue to service the African clientele in the same way that everyone does in the mainstream. This is evidenced by the lack of focus on spirituality and affect as well as their discomfort with the cosmic view of life as presented by African clans. Some social workers in health-care reported that they would not be willing to engage on any issues beyond the objective aspects of psychosocial issues in the health care context and what is objectively viewed as being in the best interest of the patient as their client. They reported that they would, however, be open to hear and listen to variant views, but would not allow such to define the focus of their intervention. This implies that a false impression of self-determination will be created when in fact the social workers continues to impose on the clients what they belief is in their best interest without due regard for what the client deems important in line with their lived experiences. This situation points to the unjust and unethical nature of social work practice in the African context. It requires urgent redress.

On the other hand, social workers from the Department of Social Development (DSD) interviewed had a similar conceptualisation of family as expressed by the social workers in health care settings seen as referring to a conjugal pair and their children. However, the DSD social workers added the notion of an extended family which they said they would involve where necessary and as permitted by policy and law. The social workers confirmed that they dealt with cases of families (Western) involving

children with DS, although their interventions were never aimed at the family as a whole. They reported that their work with African families is guided by specific service delivery regulations and policy frameworks, for instance, foster care policy as their main focus. This, according to the participants, leaves no room for explorations of cultural fit as such issues do not form part of their duties. Most of the DSD social workers interviewed were involved in foster care intake, case management and a few social workers were from the disability programme.

*“We focus on foster care... no counselling, no work with families, no group work and nothing developmental.”*

Some of the social workers interviewed reported that when they work with Africans they take off their social work cap and relate to them as Africans. They are able to observe all cultural norms governing social interactions, but would seldom touch on cultural issues.

*“When I get to an African family, I speak an African language and relate to them in an African way.”*

The social workers from the DSD expressing the above sentiments seem to believe that cultural relevance implies using the same language as clients, addressing and interacting with them in a manner that is culturally appropriate and expected such as avoiding eye contact, bowing and calling them with their title and surname. They do not see how the cultural orientation of African clans can be integrated to the content of the helping process. However, it is interesting that even the conventional process of social work intervention is not followed despite the DSD social workers being aware of it. For example, the social workers reported that they do not contract, and they do not follow the traditional social work process with planned sessions and they do not terminate. They reported that they do not do follow-ups, no counselling process, no confidentiality, no social work records kept or process notes, but they only focus on specific tasks that need attention such as completion of administrative documents linked to the statutory function and general administrative requirements for various programmes offered such as foster care and others. When asked for social work files, they all said they did not have as they do not write process notes and do not follow any process. They only

complete intake forms and thereafter complete all relevant administrative documents related to the programme concerned.

*“We are made to do things that any other person can do, whether they are trained social workers or not...”*

The DSD social workers could not classify any of their work within a particular method of social work. Not even casework or what is commonly known as work with individuals and families featured in their work.

*“There are no social work services within the DSD, but foster care administration.”*

Asked whether they regarded what they were doing in the field as social work, the participants from the DSD conceded that, although they regarded themselves as social workers as did the public and communities they served, they did not consider their work as social work or even professional for that matter.

The social workers in the community face similar challenges of lack of resources as those in health care settings. The lack of professional standing and autonomy was also a big issue for them. Unlike those in health care settings with some limited level of professional standing, the social workers from the DSD did not have a sense of professional standing and autonomy. They felt that the kind of work they performed did not require any formal training and was totally unrelated to what they studied at the university as part of the social work programme.

*“None of what we were taught at schools applies in practice.”*

They reported that working for the government meant that they will do what the government requires them to do regardless of whether it falls within the professional scope of practice of social work or not. Some reported that at times they are called in to facilitate politically motivated initiatives that are clearly outside the scope of practice of social work.

*“We are used by other professionals and politicians to push their agendas. Whenever there is a campaign, we are instructed to distribute food parcels, particularly closer to election time. We complain all the time about political interference, but no one seems to care.”*

The DSD social workers attributed these anomalies such as political interference to the fact that most of their line-managers/principals are not social workers. The management have little or no understanding of how social work as a profession operates. Consequently, there is no requisite infrastructure to enable them to do proper professional social work. There was a general consensus that what they practice in the field is drastically different from what they were taught at university when they studied social work.

*“Our work is not driven by professionalism, but regulations which are not from social work. We are not given adequate time and resources to conduct proper and professional social work interventions. When you handle foster care cases all they expect is statistics about how many cases are finalised and how many are outstanding. They are never concerned about the process and the relationship of process to quality and volume of work. All supervisors want to do is tick boxes.”*

Their practice in reality violates almost all principles and values espoused by the profession to an extent that they believe what they are practicing is not social work. The above situation impacted negatively on their motivation and morale.

*“We are confused, there is no space for social work in what we do, but they use social workers.”*

Consequently, some of the DSD social workers were considering or actively involved in alternative further studies, mainly in psychology and sociology as they did not see any career path or future professional advancement in social work.

*“The morale is very low. There is no challenge in this work because you do one same thing every day, things that are not part of your profession. As a result we feel*

*displaced and lost. We end up searching for other professional homes. Most of us are studying, but not social work. We opt for psychology and sociology.”*

*“I decided to study law because I do not get any job satisfaction from social work.”*

*“I am considering doing EAP partly because social work is not paying well and I do not enjoy what I am doing.”*

When asked about the African culture and tradition and its relevance to social work practice, the DSD social workers reported that it is important that social work practice in South Africa align itself with the African worldview. They also emphasised that this must also form part of the curriculum and training of social workers. They strongly felt that government policies and the legislative framework should be aligned to the African worldview to avoid conflicts. The current legal framework was viewed as countering the African worldview and therefore making it difficult for social workers to accommodate African practices. For instance, one social worker highlighted several challenges encountered when dealing with unmarried couples. According to the social worker the challenges come as a result of the unconditional legal rights and responsibilities given to biological parents regardless of whether they are married or not married. This, according to the social worker, is in direct conflict with the traditional regulations that prohibit any biological father from exercising any right and responsibility over a child born out of wedlock. According to customary law such rights and responsibilities remain exclusively reserved to the maternal parents/family until such time that the biological father pays ‘lobola’(bride prize) and declared married by both families.

*“As an African, I understand why the maternal family would not allow a man who has not paid lobola such rights and responsibilities, but the law suggests otherwise.”*

Contrary to social work in health care settings, the DSD is a primary setting for social work on the basis that social work services form part of the primary and core function of the department. Thus, the department as a custodian of social development and welfare services has an opportunity to develop systems and processes consistent with the modus operandi of social work so that services are rendered in a more effective and efficient manner as researched and theorised by social work scholars. One would

expect that the DSD would have the necessary political mandate and will to plan and deploy both financial and human resources, laws and regulatory frameworks necessary for delivery of user-friendly, contextually relevant and responsive social work services. Nevertheless, the researcher underscores the fact that the DSD as an institution is not necessarily a custodian of social work. Neither should social workers hold an actual or perceived view that the DSD sets parameters and context for social work practice. The DSD is a political institution that advances the political objectives and interests of the ruling political party and its underlying ideology. Thus, the DSD set parameters and institutional arrangements for the delivery of social development and welfare services in line with the governing political dispensation and policy framework. Social work as a profession must transcend the narrow political vision and interest of the governing political system and focus on the socio-economic and cultural conditions defining the context of the people it serves. This will enable social work to escape the conundrum and accordingly occupy an independent and neutral position from which it can engage, analyse, critique and provide alternatives on the basis of the best interest of the people it serves. With such independence, social work will be able to deliver services without being dictated upon by the political whims of the current government as historically experienced in the past. It was on the basis of the same conundrum that social workers were regarded by the current government as the 'foot soldiers of apartheid' (Earle, 2008:15). It is the same conundrum that led Smith (2014:325) to conclude that social work's gullibility to political influence resulted in its development in South Africa being shaped by factors and forces of colonisation and apartheid.

The above may also explain what has been revealed in this study pointing to a disjuncture between social work as taught by training institutions and pronounced through its statutory and regulatory bodies and that which is practiced within government departments. In fact, the data seem to suggest that the tasks that social workers within the DSD are required and made to perform do not fall within the scope of practice of social work. This raises serious questions for both the social work practitioners, policy makers and social work scholars.

As propounded by Sewpaul and Jones (2005:223), the prime goal of the social work profession is to promote social development, social change, social justice, empowerment and liberation of people. Accordingly, contemporary social work should

adopt a human rights perspective which reinforces the social work profession's belief in the worth and dignity of all human beings and their inherent capacity for purposeful change. It is against this backdrop that the researcher deduces, therefore, that contemporary social work is indeed alerted to the fact that social, cultural, economic, political and environmental conditions may impact negatively on human well-being and therefore need to be given attention in social work.

Accordingly, one would expect that the African clans raising children with DS should have received social work services and benefited greatly from the developmental approach espoused above by Sewpaul and Jones (2005:223) as well as a holistic approach to needs and social problems that take into account the social, cultural, economic, political and environmental conditions. Furthermore, on the basis of the above assertions, it would be expected that the theory and practice of social work would be foregrounded on an appreciation of both universal as well as indigenous knowledge systems. In the spirit of the sentiments expressed by Sewpaul and Holscher (2004:100), contemporary social work scholars "...have the power of criticism, and must not, in the name of objectivity and science, distance themselves from the power relations that exclude, oppress, subjugate, exploit and diminish other human beings". In respect of the foregoing, Ledwith (2001:171) cautions that "the political nature of education either situates educators as agents of the state or as agents of transformative change: either perpetuating the status quo or creating the context to question." In this regard, Patel (2005:370) maintains that it is essential that new graduates are critical thinkers with reflexive competence in order to respond to new realities. However, the data from the ground suggest otherwise. It would seem that social work graduates have been reduced to mere agents of the state perpetuating the status quo with no critical professional insight and in the process not able to provide services that are responsive to the needs of their clients.

#### **Sub-theme 4.2: Social workers' views on the current social work services rendered to African clients**

Some social workers interviewed were of the view that the lack of fit that exists between social work and the cultural orientation of African clans highlighted the need for social workers to adapt social work practice to the African cultural and traditional

practices. They stressed that there are sharp differences between how Africans live as compared to whites and, in due consideration, social work practice with Africans should be adapted to respond directly to the African way of life.

*“Social work is a western idea and does not fit well with how we do things as Africans. It means that we need to find ways of adapting the theories to fit in with our culture and tradition.”*

*“We definitely need to adapt social work to the culture of Africans because whatever we learn at school does not work for black people.”*

*“Our culture is very different from white people’s culture. What we learnt during training seems to fit well with a white culture, but when it comes to us, it does not fit.”*

Social workers also noted the potential conflict linked to different ways of knowing and understanding the world. However, they emphasised that such differences can be managed better through open and honest conversations.

*“The African people have belief systems and practices that are very unique. For example, most of the rituals, ‘muti’ and ceremonies that they conduct are aimed at addressing particular challenges and they work for them. You cannot dispute that simply because you do not believe in it. They believe in it and it works for them. Therefore, we need to find ways of accommodating them and design approaches that talk to them like they did in medicine. They have accommodated some of the ‘muti’ that has been proven to work and is not harmful. As long as it does not harm or hurt anyone, let it be.”*

They cautioned that to achieve this, social workers need to become more assertive and stop trying to fit in, but set norms and standards that will determine what they do as professionals instead of being told by others what they must do.

*“It is high time that social workers learn to be firm and act like professionals.”*

*“We cannot practice social work the same way in rural and urban areas, traditional and westernised contexts. We need to be flexible enough to allow an understanding of contextual issues to determine how we intervene.”*

*“Social workers must appreciate the value of the strengths and assets inherent in certain traditional contexts and tap into them.”*

*“We are aware that social work theories are based on western worldviews, we need to develop new theories based on local culture and tradition.”*

However, there were differences in this regard. Some social workers practising within health care settings were adamant that their interventions do not in any way conflict with African culture. They felt that they are able to adapt their interventions accordingly whenever they deal with Africans to ensure that there is no tension.

*“There is no lack of fit; social work is adaptable to all cultures. You just need to be aware of the different cultures.”*

*“As long as you are not judgemental and you accept people as they are, you can work with anyone, whether African or any other nationality.”*

Some social workers disagreed, indicating that social work methods and techniques are alien to the African way of doing things. They highlighted the fact that often such a tension is modified by the fact that social workers are Africans themselves and tend to act in a manner that is consistent with African culture, something which a non-African would find it difficult to do.

*“There is a serious tension between social work practice dominated by western values and African culture. For example, the issue of sitting-up, open posture, leaning forward and maintaining eye-contact are at odds with our culture and may come across as being disrespectful. So as an African, aware of my cultural orientation, I will not do such things when working with Africans. I will not even use English, I will speak with my African client using an African language.”*

*“Anyone saying there is no conflict should stick to what they were taught and see what happens. We naturally switch from the social work way and follow the African way, but a white person will not know how to make the switch and will come across as cold to the clients.”*

There seem to be a general sense of scepticism about the professional standing of social work. It appears that the professional authority of social work is compromised by the failure of social workers to assert their professional standing in host settings while other professionals carry out their duties with the required professional authority.

The social workers within health care settings reported that they never collaborated with DSD social workers unless the client in the hospital did not have a family and as part of discharge planning they were compelled to find alternative placement for the client or when dealing with unwanted children who needed adoption. However, they reported that they have dealt with cases where African patients refused treatment on the basis of cultural or religious belief systems.

*“The dilemma created when a client refuses hospital treatment is that there is a risk of their condition worsening and as a social worker you are then expected to make sure that the patient who is your client understands and appreciates medical treatment. I always focused on what is in the best interest of the client, which is medical treatment.”*

The researcher is of the view that the sentiments encapsulated in the above statement overlooks an important element of the client’s worldview and existential condition. Consequently, the social worker focuses solely on the objective view of the patient’s health while ignoring the significant other aspects. Such a reductionist view is likely to miss out on the opportunities and resources linked to those aspects that are left out.

The above verbatim accounts uncovers numerous techniques that social workers use when working with Africans to address the lack of fit between social work practice and the African culture. Firstly, it is clear from the verbatim accounts that African social workers find it easy to manage the lack of fit as they easily switch from the professional techniques to the customary way of interacting with people. They are able to put aside all manner of behaviour that is known to be in conflict with the African culture such as

maintaining eye contact as they know that it appears disrespectful. It seems the use of an African language is also an important mediatory measure given that languages are culturally loaded. The researcher underscores that all these mediatory measures have a potential to alter intervention significantly to a point that a comparative analysis of a social work intervention done using an English language by a white person might differ drastically with another intervention facilitated by an African with African clients.

*“How I work with white clients is different from the way I work with Africans and I do not think a white person working with African clients will work the same way as I do. I do not even think that the level of satisfaction by our African clients will be the same.”*

The DSD social workers were mainly in agreement that social work with African people cannot be the same as social work practice with white people as the two groups have different cultural orientations.

*“African families have a completely different way of life and require that whoever works with them understands and be able to act and talk in a manner that is consistent with African culture. There are various rules about how one addresses certain people in certain ways, how you should dress and approach people. It would be very difficult for someone from outside that cultural background to comply with all those rules.”*

They believed that they are in a much better position to connect better with fellow Africans and did not believe that a white social worker would be in a position to connect with African people because of the cultural differences.

*“A white person going to a traditional African family would be a disaster. I would not recommend that, unless they are trained thoroughly on African culture.”*

However, their biggest frustration was that they were not even given an opportunity to practice social work. They reported that their work in government reduces them to mere administrators of government social services which are not consistent with what they were trained to do. They indicated that the tasks given to them to perform do not fall within the scope of practice of social work and is not foregrounded on social work values and principles. However, they all confirmed that the African families are

underpinned by a different value system and worldview that do not strike resonance in professional social work practice as theorised in literature.

Thus, in summary the theme under discussion revealed that there is lack of fit between social work services and the cultural orientation of Africans. The data reveals that the practitioners are not practicing social work as theorised. Furthermore, there seems to be a general disregard for the African worldview and cultural thought. The omission of the African worldview and cultural thought may be attributed to a number of factors including the fact that social workers may have failed to start where the client was and consequently missing out on important information. The social workers may also have failed to see things the same way the client sees them by allowing the client to lead the process. The social workers may have ignored critical contextual issues that shaped clients' reality.

Secondly, where social work intervention was conducted such as in the health care settings, it was not holistic. The individual targeted was either the mother or the child and the two were targeted depending on the nature of their presenting challenge. For instance, if the mother presented with a lack of proper accommodation for the child, the social worker would work towards addressing such a problem. If the child needs institutionalisation in the social worker's view, he or she would work towards getting the child into an appropriate institution. Again, the lack of a holistic view of the client's situation as revealed by the findings seems to have been an act of omission on the part of the social workers. This has been demonstrated by the records of verbatim accounts shared in the discussion.

The above situation contradicts social work theory as espoused by Cummins et al. (2006:6) who assert that social work intervention plans should take into account the social systems that have an impact on social functioning in a holistic and integrated manner. The findings point to a worrying trend in the practice of social work veering away from its frame of reference. Cummins et al. (2006:6) have accordingly lamented that the unique focus on the person-in-environment is one aspect that set social work as a helping profession apart from others. They further argue that the helping process in social work begins with engagement and assessment. It is therefore expected that a trained and qualified social worker would undertake a thorough assessment as they

engage with clients about their presenting problem in order to find underlying issues that give birth and influence the presenting problem. Accordingly, Cummins et al. (2006:5) were bold to emphasize that assessment is an on-going process in social work. Meaning that, as the social workers engage with the clients, they should be continuously assessing the person in his or her environment. If this is done, there is no possibility that issues that are important for the client could be missed.

It is through an in-depth assessment in line with the person-in-environment perspective that social workers are able to connect the person to significant systems and factors in his/her social environment including issues of culture. However, the social workers interviewed reported that there was lack of fit between what they did and the African worldview, but this was worsened by the fact that they were not even doing what is expected from a social work point of view.

The findings on the above points are consistent with arguments made by the proponents of indigenisation in social work (Midgley, 2008; Thabede, 2008; Gray, 2005; Osei-Hwedie, 2002) that given the fact that social work theory and practice is based on the Western worldview, its roles in Africa must be adapted to ensure relevance and appropriateness to the needs of the African socio-cultural context.

The findings point to the fact that the intervention of social workers was limited to the dictates of statutory provisions and policy frameworks and ignored all social work principles and values. This can be attributed to the influence of Western values on the South African legal and welfare system. The data collected from social workers regarding their services pointed to an individual instead of a collective focus. Following Thabede's (2008:235) argument, individual concerns are subordinate to the group interest in the African context and most activities are based on group effort. As a result, the social workers rendering services to African clients have to be aware of this state of affairs, for them to be in a position to adapt their interventions accordingly.

#### **Sub-theme 4.3: Social workers' suggestions for improvement of social work services to African families raising children with DS?**

The social workers practicing within health care settings suggested that there is an urgent need to beef up the available human resources to allow for a more comprehensive intervention that embraces the domain of practice of social work and allow for the infusion of a developmental paradigm/approach. They complained that there is a critical shortage of social work staff resulting in them only attending to prioritised cases and leaving out the majority of clients who need their services.

*“Our situation here in the health care field is difficult. We would like as social workers to attend to any person in need of social work assistance and give them proper social work services, but it is not possible. We can only see the neediest patients and intervene within a short period of time. When the doctor decides to discharge, it does not matter what you have done and still have to do, the patient gets discharged.”*

*“We know we could do better. In contemporary social work we talk developmental social work, but how do you put that into practice in an environment like this? We wish we could practice developmental social work, but it is difficult here to do that and we end up doing what we can. Social workers must be given enough resources to serve African clans properly in line with their culture. They must be given more autonomy to assess their clients and come up with an intervention plan independently and be able to implement the plan.”*

*“The situation compels us to focus on case work and mainly short-term and brief interventions. We are not able to move beyond case work to embrace other methods including group and community work. How are we going to work on services to African families. There seems to be no space as we are over-stretched as it is now. Improving services to become more culturally relevant to Africans is a challenge in itself. Management will have to be brought in to assist us.”*

This is consistent with the assertion made by several South African social work scholars who noted that, historically, social work in South Africa was based on a clinical approach and a treatment-oriented emphasis of intervention focusing on case and group work undergirded by a residual welfare system (Smith, 2008:374; Patel, 2005:98). However, Patel (2005:58) further notes that the above situation has since changed with the adoption of a new developmental welfare system with concomitant

changes in the conceptualisation of social work training and practice ushered by the Post-1994 political transition. Contrary to the above assertion, the findings revealed an astonishing revelation pointing to stagnation with old ways of doing things as revealed in the verbatim accounts by social workers in health care. The social workers in health care confirmed in no uncertain terms that their work remains clinical and treatment oriented. They brought this to light through a series of verbatim reflections that appear to be at odds with Patel's claim that social work practice in South Africa is changing towards a developmental approach that moves beyond case and group work. It seems the only change is on paper, not in practice. The real challenge seems to be the fact that the shift to a developmental social work was only facilitated at a conceptual level. No structural and process changes were contemplated to allow for the accommodation of the developmental approach. Therefore, lessons should be learnt from this experience for the implementation of Afrocentric social work services. For the services to be effectively implemented, proper institutional changes will have to be made to pave a way for implementation. Otherwise it will only exist on paper and never trickle down to implementation.

However, the health care social workers felt strongly that social workers need to be trained on an African cultural orientation and worldview, particularly those that are not of African descent so that they know what to expect from African clients.

*"Social work education has equipped us with skills and competencies that enable us to work across different cultures. But it is important for us to know the cultures of our clients. So I will recommend that for those social workers who are not of African descent, be given some education on African culture and traditions so that they can understand Africans better. Without such understanding, they may find themselves missing out on important cultural issues."*

The social workers also suggested that the training of social workers be transformed to embrace the African worldview. This, according to the social workers in the health care sector, should also include research and development of new models based on the African paradigm.

*“All social work training institutions should teach students about the African worldview paradigm. They must instil this knowledge in potential social workers while in training. At the same time the organisations and government institutions and departments employing social workers should look into changing the way they work to accommodate the African worldview.”*

*“The problem lies with the organisations, not social workers. The organisations that we serve were never designed for serving African people. They need to be Africanised first, then a safe environment will be created for ushering in indigenous social work services. Otherwise, it will not work.”*

*“You cannot do anything African as a professional because everyone will see that as unprofessional. We need to leave African culture outside the professional space because the two do not go together.”*

*“I believe it is time for the African way to be followed, we are in Africa. My suggestion is for this to be formalised in the social work education system, research and in practice. We need models and approaches that are tried and tested through research. We need to educate everyone involved about them.”*

*“I think most of the theories that are there, are working well. We should not throw them away, but we can gradually introduce new things that talk to African culture. It must be gradual and not be disruptive.”*

The social workers suggested that the African worldview be infused into the social work curriculum at universities and be incorporated into practice through transformation of the various models, techniques and methods used in social work interventions.

*“It is important that social workers understand the African worldview, adding it to the curriculum would help especially those students that are not of African descent, but even Africans need to be reminded of their own belief systems.”*

*“We need to transform the way we do things. The current models, techniques and methods are not accommodative of the African culture and they need to be changed. We need to develop new models in line with African culture and belief systems”*

The above statements seem to suggest that the health care environment may find it difficult to accommodate changes to Afrocentric social work services due to its rigid nature. The social workers recognise the need for change, yet they caution that the type of change introduced must not be hasty and disruptive, but gradual and fortified by evidence-based information emanating from research which will lead to the development of relevant theories and models for assisting African clans raising children with DS. Social workers are concerned by the fact that it is difficult as of now to effect improvements on the current service offerings and wonder if introducing further changes relating to Afrocentric services will materialise. The ecosystems theory was used to appreciate the significance of the issues raised by the social workers regarding the interdependence and relationships between the services they render and organisational factors including leadership and management, allocation of resources, openness to change as well as other external role players such as social work education institutions and research. The ecosystems theory assisted the researcher in addressing the relationship, interaction and interdependence between social workers as employees, their work and the employer organisation as well as other external role players. According to Bronfenbrenner (cited in Darling, 2007:203), there is a dynamic interplay between the different sub-systems and different levels of environments and that human development is bounded by context, culture and history. This is consistent with the Afrocentric philosophy's principle of oneness and interconnectedness of all elements in the cosmic system. Therefore, it is important that when considering the suggested improvement, social workers should take into consideration the interplay between various levels in the work environment as well as different sub-systems.

The social workers from the DSD suggested that they should be given professional autonomy, space and resources to put social work theory into practice instead of merely performing tasks that any other person regardless of professional background can perform which in their view undermines the professional role and mandate of social work. In this way, they would be able to adapt their work to create relevance for the African clans raising children with DS. Similar to their counterparts in the health care

field, they felt that in the current state of affairs where they are not able to even practice the conventional social work methods, it would seem even more impossible to contemplate improving services to become culturally relevant to the needs of African clans raising children with DS. They also called for mainstreaming of the African worldview in social work education, research and practice including vigorous dissemination of information about it in different available mediums of communication to all social workers on the matter of the African world view.

*“We need to popularise the idea of relevance through embracing the African worldview in our work. Let it become a buzz word and get people talking about it, social workers and the public. Our clients too need to know that they are entitled to a service that is responsive and culturally relevant.”*

*“It is important that social work services are improved to become relevant to African families’ cultural orientation. The challenge is that there are so many challenges facing the profession that it makes one wonder where do we start. But I suggest we make sure that this message trickles down to every corner. Let the education institutions transform and Africanise, the researchers too must Africanise their research methods and outputs, the social workers in practice as well as the regulatory body, the SACSSP must see to it that the face of social work practice changes to reflect Africa. This is already happening in smaller isolated pockets in practice. For example, when a man comes and complains to the social worker about not being allowed to see his own child born outside marriage, the social worker does not impose on the family, but advises the man accordingly that it is a customary requirement that he marries to have full rights to his child.”*

*“We need to market the noble idea of Africanising social work, let everyone talk about it. Use social media, newsletters, journals, newspapers, facebook etc. to spread the work so that anyone not working on Africanising social work may not feel the discomfort.”*

*“We need to go back to the basics. We are qualified social workers. We are professionals. We cannot be working like non-professionals who get told what to do and how to do it. We are capable of identifying gaps and coming up with remedies*

*including how best to create relevance to the African worldview. This will materialise only if we can be given the professional space to do this.”*

*“Social work in public service needs to be revitalised. What we do here is not social work. How do you instruct a professional somebody to go and distribute food parcels?”*

*“I think the whole social work fraternity, the higher education institutions and the council (SACSSP) need to take note of this situation and do something urgently before the profession dies a natural death. Social workers need to speak in one voice and assert their professional standing.”*

*“We came out of universities excited that we are going to practice social work as we were taught, but we got a shock of our lives. We realised that what we were taught only exists on paper in theory. In practice, it does not exist. So why continue teaching something that does not apply... or are we missing something here? We either change what we teach or what we practice so that the two speak one language.”*

The challenge of a discrepancy between theory and practice remains a serious source of frustration for practising social workers, especially newly qualified social workers. It seems that little or nothing is being done to address this problem. To a greater extent, it can also be argued that the challenge has not been largely recognised by the stakeholders including the regulatory body (SACSSP), researchers and social work education institutions.

The general morale of social workers in the DSD seemed to be low. The DSD social workers were disillusioned and considering alternative career paths. Several of them were already furthering their studies mainly in psychology, sociology or law. Very few would consider postgraduate studies in social work, but rather preferred to branch out to other related disciplines. It appeared that most social workers were grappling with occupational stress due to a general lack of job satisfaction and low morale. The social workers attributed the situation to a number of factors including the perceived low status of the social work profession in society in comparison to others, the generally low wages and the fact that work conditions are generally uncondusive and unbearably characterised by a lack of resources. Although this does not directly relate to their work

with the African clans raising children with DS, it does have a general influence on the manner in which they work with any client system, including African clans raising children with DS as highlighted by the ecosystems theory. Thus an improvement in this regard would automatically translate into an improvement in services to the African clans raising children with DS.

*“There is a lot of burn-out in social work. There is no job satisfaction. People are stressed and the same people are expected to alleviate other people’s stresses, how is that possible? The first step would be to improve the working conditions of social workers including salaries and then give them professional autonomy to practice social work as they know it”*

*“We work under extreme conditions, there are no adequate offices. We don’t even have therapy or counselling rooms for our clients and as a result there is no privacy for the clients. All these need to be addressed as a matter of urgency. Allocate adequate resources to allow social workers to perform their professional duties in a conducive environment”*

*“We share limited vehicles, but yet we are expected to be in communities. We work in rural areas where the roads are bad and dangerous. Yet, we are not given adequate and proper vehicles like 4x4 to be able to access the remote villages. Therefore, the suggestion is that social workers should be allocated adequate resources including vehicles to be able to visit families”*

*“We are paid very low salaries. If you consider how hard you work under extremely dangerous conditions with limited support, but at the end of the month you cannot afford to meet your basic financial needs. You end up blacklisted and stressed financially. How are you expected to survive? The only option available is to move to other professions that promise more lucrative salaries. Therefore the first step towards improving services is to improve the working conditions of social workers. When social workers are happy, they will make sure they do the best for their clients”*

*“If they can increase our salaries to a level that is at par with other professionals like psychologists and improve working conditions it would make a huge difference. We*

*would be able to direct our energies where it matters most; our jobs and do it to the best of our abilities.”*

The social workers agreed that social work practiced with different client systems should be different, relevant and responsive to the specific client systems they serve. They all agreed that the cultural heritage of the African clientele was not reflected in the theoretical knowledge base of social work and instead western worldviews dominated the theoretical landscape of social work. This, according to social workers, called for the development of culturally specific theories, methods and techniques that will be taught to social workers across the spectrum if they want to practice in South Africa.

*“There is a discrepancy between what we are taught and the reality of life in African communities. Black people have different belief systems, traditions and cultural practices that they hold dear and this influences everything they do. As social workers we need to work within that framework because there are strengths and resources that we could build on. But because we are being trained in a western dominated social work, we often down play African traditions. So the training of social workers needs to change”*

*“We are black social workers working with black clients, but we do not appreciate black culture and traditions. Some of us don’t even understand black culture because of the domination of white culture through media and the education system that favours white culture. So I suggest that social workers should be given clear instructions by the SACSSP to assist African families using the African worldview and report on it in some way and be incentivised with CPD points so that there can be standardisation eventually. African theories, models and approaches will emerge out of this.”*

There was consensus that social work practice in South Africa requires an urgent review and revitalisation. This should include the re-training of social workers on African worldviews and including it in the curriculum for social workers being currently trained. It should also include more research on the African worldview so as to build new theories and models. Social workers also felt that social workers should encourage on-going and continuous giving and receiving of feedback between social

work education, research and practice to ensure continuous evidence-based improvement of the professional content.

*“We need to include African culture and tradition in the curriculum so that everyone who trains as a social worker in South Africa gets exposed to black culture. White students as well can learn.”*

*“I will strongly recommend that the social work curriculum be transformed to reflect Africa and its cultural heritage and traditions. This must also include research on African culture so that we are kept up to date with the changes as nothing is static.”*

*“It is our responsibility as black social workers to push for the inclusion of black culture in the social work curriculum. The universities in South Africa should make sure that they transform their curricula to reflect the different traditions of Africans. The South African Council for Social Services Professions (SACSSP) too should come to the party and make sure that it pressures universities to do this.”*

It is evident from the suggestions given by social workers that the lack of fit between social work theory/practice and the African worldview when rendering social work services to African families raising children with DS. This may be partly attributable to the fact that the world of professional social work generally at a global scale is deeply embedded within the Euro-North American worldview as has been shown in the literature (Brydon, 2011:156; Gray, 2005:235; Sewpaul, 2006:213). Interestingly, the participants also raised an important point about the role of the SACSSP in this regard. It is indeed incumbent upon the SACSSP as a guardian of the needs and interests of social work clients to ensure that the profession and academic discipline of social work is responsive and relevant to the contextual factors surrounding the social work clientele such as the historical socio-cultural, economic and political factors.

### **5.3 Summary of the chapter**

This chapter presented the discussion on the findings of this study. The discussion was kick-started by the analysis and interpretations of the data that was obtained from the African clans raising children with DS. This was followed by the discussion on the

analysis and interpretation of the data obtained from the social workers rendering services to the African clans raising children with DS. The findings revealed that not all social work practitioners are engaged in social work practice as seen with the social workers employed by DSD. The findings also revealed that where social workers are engaged in some form of social work practice, such form of practice as seen with social work in health care, remains clinical and focuses exclusively on individual and rarely group work, despite the call for a paradigm shift towards a developmental approach. A positive aspect coming out of the data is that social workers seem to be aware of the developmental approach from their training. This means that institutions of higher learning seem to have succeeded in infusing this approach in their curriculum. A more worrying fact is that a bigger segment of the social work fraternity found within the DSD seems to be practicing something else other than social work albeit in the name of social work.

## **CHAPER SIX**

### **AFROCENTRIC SOCIAL WORK PRACTICE GUIDELINES FOR ASSISTING AFRICAN CLANS RAISING CHILDREN WITH DS**

#### **6.1 Introduction**

The following guidelines are referred to as 'Afrocentric social work practice guidelines' on the grounds that the literature on indigenous social work in Africa is referred to as Afrocentric social work and not indigenous social work. The developed Afrocentric social work practice guidelines for assisting African families raising children with DS are based on the research findings of this study as discussed in chapter 5 of this thesis. The guidelines move away from the use of the word family and embrace the use of a clan found in the African context as indicated in the discussion of the findings in chapter 5. Thus the guidelines are clan-centred.

The dawn of the 21<sup>st</sup> century has witnessed a phenomenal proliferation and recognition of the need for indigenous applied social sciences, including the academic discipline and profession of social work. Social work scholars in post-colonial contexts across the world have for a long time argued that social work theory and practice developed in western contexts is ineffective and culturally irrelevant for social challenges in non-western contexts (Mungai, 2015:66; Brydon, 2011:150; Midgley, 2008:31; Thabede, 2008:235; Gray, 2004:625; Graham, 2002:19; Osei-Hwedie, 2002:312; Schiele, 2000:15). Specifically, Schiele (1997:803) argues that there are two fundamental problems with the current form and outlook of the social work profession which necessitates exploration of alternative typologies. Firstly, it is problematic that social work practice is based on theories and paradigms that are underpinned by a Eurocentric worldview. He further posits that the Eurocentric worldview is primarily based on the geo-historical, political, economic and philosophical traditions of Europe, characterized by a linear, individualistic, materialistic and rationalistic understanding of reality and being, with the exception of the ecological perspective. However, Schiele acknowledges that the use of an ecological perspective in social work remains limited to the linear, individualistic and materialistic conceptualisation (Schiele, 1997:803). Secondly, Schiele (1997:803) notes that the social work profession remains silent on the cultural values of people of color. The researcher notes that subsequent to

Schiele's assertions, various theoretical interventions emerged to address the domination of the Eurocentric worldview and cultural orientation on the social work knowledge base including literature on cultural competency and cultural sensitive social work (Yunong & Xiong, 2012:48; Lee & Greene, 2011:35). However, these interventions are arguably ineffective in the face of prevailing institutional and structural basis of cultural oppression. Leading indigenization scholars such as Brydon (2011:162); Askeland and Payne (2006:741); Gray and Allegritti (2002:332) call for cross-cultural practice with emphasis on extensive dialogue between cultural groups on principles, ethical norms and appropriate practice towards the achievement of cultural relativity and a truly diverse and cross-cultural world without actual or perceived hierarchy. These guidelines represent one form of contribution towards achieving the above objective. This is based on the firm idea that the cultural heritage of Africans has not been used as a theoretical base to develop new social work practice models. Instead, existing Eurocentrically oriented practice-based models are adapted to address challenges of African people, ineluctably resulting in a glaring lack of cultural relevance.

In her editorial of the Asia Pacific Journal of Social Work and Development, Ng (2014:127) undertook a comparative analysis of the changes brought forth by the new definition from the old. Amongst changes noted is the addition of the academic discipline, replacement of problem solving with social cohesion, the addition of collective responsibility and respect for diversity and most importantly the addition of **indigenous knowledge systems** as one of the sources of social work knowledge. The inclusion of indigenous knowledges as part of the knowledge base of social work by the IFSW in 2014 signaled recognition at a global level of the significance of indigenous knowledges to the social work profession and academic discipline. It propelled yet another wave of scholarly contributions at an international level regarding the significance of this historically neglected knowledge area.

Like many developing countries, South Africa as a developmental state has over the years consistently expressed commitment to the improvement of the quality of social work services such that there can be a contribution to nation building. The adoption of the White Paper for Social Welfare (Department of Welfare, 1997) and the subsequent Report on the Review of the White Paper for Social Welfare 1997 (Department of

Social Development, 2016) form part of indications of the commitment. The government has recently embarked on a review of the white paper wherein a new focus on indigenization has been introduced. The researcher observed that the government of South Africa clearly expressed its commitment to this course. This is contrary to what is going on at the grassroots level as shown by the findings of this study, where social workers are not given space to practice social work.

The institutions of higher learning have also weighed in on the need to indigenize knowledge coupled with a call for decolonization of knowledge, being and power. South Africa has recently witnessed nation-wide student protests in the past two years of 2015 and 2016 at universities where students and some stakeholders have come together to demand free education, acceleration of transformation, particularly the call for decolonization of university spaces and curriculum. It is against this backdrop that the researcher argues for a critical re-examination of the intersecting relations between power, knowledge and being/identity and their concomitant influence on humanity, particularly in the context of social work practice, research and education.

The researcher based his assertions above on the premise that social work as an applied profession in post-colonial Africa may want to produce social work graduates who will serve as social change agents grounded and centred in Africa. The profession may not wish to end up with graduates who do not know who they are, where they came from and, by implication, where they are going! The indigenous approach to African social work has, as its hallmark the centering of social work service in Africa's cultural heritage, socio-political and economic history, knowledge systems and intellectual traditions. This implies Afrocentric clan-centred social work. It also encompasses the African worldview, philosophy and cultural thought. To effectively put Afrocentric clan-centred social care principles into practice and lead the change process, South African social workers require practice guidelines that are specifically tailored to address contextual issues and the needs of the African clientele. Thus, clan-centeredness will have to be at the core of Afrocentric social work, hence the twinning of the two in this chapter. The notion of clan-centred social work is an equivalent and a qualification of the concept client-centredness in conventional client care literature. This implies that the African clan, not the individual or couple constitutes the social

work client-system. The initial idea of the African family as used in the research topic has been abandoned as it does not resonate with the lived experiences of Africans.

The vast literature on social work practice indicates that practice guidelines can increase evidence-based practice and improve the outcomes of social work intervention (Gould, 2010:93; Howard & Jenson, 1999:283; Wambach, Haynes & White, 1999:322; Williams & Lanigan, 1999:338). Drawing on postulations by the above literature, the researcher advances that the development of evidence-based practice guidelines for social work could also promote more informed decision-making by the client (African clans), improve training in schools of social work, encourage more cost-effective and accountable practice, and help formalize emerging indigenous knowledge systems in what is perceived to be controversial practice areas such as Afrocentric or indigenous social work. Eventually, through these interventions, the proverbial divide between the social work practitioner and researcher is bridged through the establishment and strengthening of the scientific foundations of social work practice (Gould, 2010:95). It is hoped that these Afrocentric social work practice guidelines will go a long way to help improve the experiences of African clans raising children with DS who access social work services, given that the social worker who provides services to these clans would understand their world view better, leading to appropriate interventions. Therefore, this set of Afrocentric social work practice guidelines do not serve to remotely substitute existing theories nor claim a superior position in a hierarchical presentation of theories, but serves as an addition in line with Brydon's (2011:160) framework for cultural relativity that propagates the need to make use of a litany of theories, models and paradigms sourced from a variety of cultural contexts when dealing with people from or of multicultural backgrounds and origins.

The guidelines were developed under the guidance of the African existential philosophical lens which was used concurrently with three theoretical frameworks, which are social constructionism/constructivism; the eco-systems theory and the strengths perspective. The philosophical lens and the theoretical frameworks played a vital role in guiding the analysis of data that formed the basis for developing these practice guidelines. The African existential philosophy enabled the researcher to effectively use the lived experiences of African clans raising children with DS as a unit of analysis in order to arrive at an in-depth understanding of their experiences and the

meaning attached to the experiences. Such experiences could not have been adequately understood from a Eurocentric perspective. This philosophical stance also enabled the researcher to analyse and understand the data within the context of the African worldview undergirding the lived experiences of Africans. While the use of the social constructionist/constructivist theory within the context of the African existential philosophy assisted the researcher to appreciate that knowledge systems forming part of the African clan system are socially constructed at a collective and personal/individual level, the use of the ecosystems theory and the strengths perspective within the context of the African existential philosophy enabled the researcher to view the African clan as a system forming part of a bigger cosmic environment made up of various interrelated and interdependent parts that are designed to work together to achieve harmony. The strengths perspective was used to identify various opportunities and areas of strength and resilience keeping the clan system intact and functioning optimally.

The developed guidelines outlined in this chapter are tailored to the provision of Afrocentric social work services to African clans raising children with DS (in health care settings, and community-based social services). They are designed to be used in addition to other policies and standards operating procedure documents that are available in the South African social services and welfare landscape. This readily calls to mind cautionary note by Sherr (2006:12) that the acceptance and application of the Afrocentric paradigm does not mean the exclusion of other theoretical paradigms. Instead, it means an additional, fresh and legitimate approach for understanding human behavior, analyzing policy and developing social work interventions.

This chapter comprises three main components. The first component found in section 6.2 outlines the process of developing the guidelines, definition of terms, scope of application, purpose, objectives, guiding principles for the guidelines, definition of Afrocentric social work and its attributes or principles. The second component 6.3 is made up of two subsections, namely, 6.3.1, that deals with the practice guidelines on Afrocentric social work services to African families raising children with DS, while section 6.3.2 presents guidelines on organisational factors required to support the effective implementation of Afrocentric social work services.

## **6.2 The methodology followed and framework of the guidelines**

This section discusses the methodology followed in the development of the guidelines as well as an overview of the guidelines. The overview covers the scope, purpose and objectives of the practice guidelines. Furthermore, the overview also covers the definition of key concepts used as well as the main components that make up the guidelines and their explanations. Finally, a brief overview of Afrocentric social work, including its assumptions and methods are presented.

### **❖ The Process followed in developing the guidelines**

The idea and process of developing these guidelines was motivated by the concerns raised by several African scholars as outlined in the literature review chapter of this thesis, about the lack of fit between social work methods and models developed in the Euro-North American context and African contextual issues and challenges. It also stemmed from the researcher's professional reflections on own practice experience as an African working with the African clientele in social work and the desire to make social work services more responsive and client-centred. The findings from this study presented in chapter five (5) as well as the extensive literature review in chapter three (3) and four (4) were used as the basis to draft these guidelines. The actual process of developing the practice guidelines was guided by the African existential philosophical framework, the three theoretical frameworks of social constructionism, ecosystems theory and the strengths perspective. Guided by the African existential philosophy, the researcher focused on the lived experiences of the African families to determine issues and aspects that should be covered by the practice guidelines.

### **❖ Scope of application of guidelines**

The guidelines are designed to assist the social workers in the process of providing services to African clans raising children with DS in South Africa. This covers social workers in all fields of services that are supporting African clans raising children with DS including health care settings, government welfare services and non-governmental organisations. Although the following Afrocentric practice guidelines are designed for social workers assisting African families raising children with DS, their applicability can be extended beyond this area and may be adapted and used in any other social work domains of practice involving people of African descent. They are designed to serve as

a professional guide to Afrocentric social work interventions from assessment, planning, intervention and evaluation of indigenous social work interventions. Furthermore, the guidelines may serve as an essential tool for planning, implementation, monitoring and evaluation of Afrocentric social work services and programmes targeting the African families raising children with DS. The main target groups are South African social workers who are involved in providing direct social work services to African families raising children with DS as well as relevant facility managers and welfare policy makers, to make their services Afrocentric so that they could be responsive to the real needs of their clientele.

#### ❖ **Purpose of the guidelines**

The purpose of these guidelines is to provide empirically-based practice guidelines on Afrocentric social work services to assist South African social workers render clan-centred services that are responsive to the needs and challenges of the African clans raising children with DS.

#### ❖ **Objectives of the guidelines**

The objectives are to:

- Explain the meaning of Afrocentric/indigenous social work and its attributes, with regard to social work interventions that involve African families raising children with DS,
- Describe recommended practices to make indigenous social work services with African families raising children with DS more relevant and clan-centred at all the agencies that provide social work services,
- Promote more authentic, genuine and active participation and mutuality in the social work helping relationship with clients of African descent as well as to improve training in schools of social work, encourage more cost-effective, accountable, relevant and responsive social work practice, and
- Contribute to the validation and formalization of the emerging stock of Afrocentric/indigenous knowledge system as a recognized knowledge area in the African social work fraternity.

#### ❖ **Components and attributes of Afrocentric and clan-centred social work**

In discussing the characteristics of Afrocentric social work, the following components have been identified and are subsequently discussed:

- The attributes of Afrocentric and clan-centred social work services and their explanations are presented in Table 7.
- A definition of Afrocentric social work,
- Identifying the origins of human and societal problems from an Afrocentric viewpoint, and
- Delineating strategies that might be applied in Afrocentric social work to empower African clans raising children with DS and enhance their potentials.

**Table 7. Components and/or attributes of Afrocentric social work services with African clans, raising children with DS and their explanations.**

Component/attri	Explanation/definition
Sacred	The African worldview emphasizes that every phenomenon regardless of its perceived or actual implications is sacred and symbolic. Contrary to the Eurocentric worldview that objectively judges phenomena and impose a dichotomous interpretation of experiences or phenomena as either good or bad; acceptable/not acceptable; and at times labels phenomena as profane/cursing/blasphemous, the African worldview puts emphasis on a deeper meaning that transcends objective judgement to embrace spirituality and affect. For instance, the birth of a child with DS may be viewed as a sacred gift from God that must be cherished for a good and bigger purpose rather than bad news or a curse that must be eliminated, hence we see fewer Africans opting for termination of affected pregnancies as compared to the prevalent use of elective termination of affected pregnancies in western communities.
Holistic	The view of everything as connected to a whole and therefore related and interdependent, contrary to the segmentation seen in the Eurocentric worldview. The birth of a child with DS is perceived to be connected to other events in the clan and that each member of the clan is related and interdependent on others as well as both physical, natural and spiritual forces in the environment. Equally, the material, spiritual and affective aspects are related and interdependent.

Unifying	The African cultural essence promotes a unifying approach to everything and, as such, dichotomies and the notion of binary oppositions or splitting when viewing diverse phenomena is disavowed. For instance, the African view on the relationships between a child perceived as normal and a child with DS or help and helped is unified to complement and complete each other. The two work together to create harmony and meet unmet needs.
Integrative	Building on the above, all things work together in an integrative manner in the African worldview contrary to the separating view held by the Eurocentric worldview. This means that when dealing with the African clan raising a child with DS, there is no fragmentation and no specialist focus on one aspect of the challenge. Instead, they are pooled together in an integrated fashion and addressed jointly. Disability is dealt with as disability regardless of the type of disability and all aspects of the disability are attended to in an integrated manner. This implies that medical treatment is integrated with psychosocial and other therapeutic interventions, material with spiritual and affective, objective with subjective aspects.
Complementarity Appositional	The African worldview emphasizes that any difference observed between humans, be it on the basis of gender, social roles or age should be viewed as complementary and appositional rather than confrontational and oppositional. For instance, the child with DS is not viewed as oppositional to what is perceived as a normal child, but complimentary. In the same manner, a bad or negative experience complements a positive one as a loss compliments a gain. Those that have the ability compliment those that do not have the ability.
Harmony	Thus, building up on the above, human relationships should be viewed from a harmonious perspective instead of conflict and tensions as found in the Eurocentric worldview. This means that the birth of a child with DS should not necessarily be viewed antagonistically in comparison to a birth of a normal child, but as harmonious and self-correcting.

Symbol	The African worldview perceives phenomena as symbolic rather than mere objects as prevalent in the Eurocentric cultural orientation. Everything including incidences such as death or birth of a child with disabilities has some meaning in the African worldview and objectification finds no expression. This means that the birth of a child with DS carries an underlying message with it. It cannot be reduced to a mere incidence.
Reciprocity	The African view of difference in human attributes such as gender, age and ability/disability focuses on opportunities for reciprocity rather than exploitation. This is in line with the principle of 'Ubuntu'. Therefore, the birth of a child with DS calls for those able-bodied to care and protect instead of exploiting the child with a disability.
Inspirational	In the same breath, any form of human differences serves as an opportunity for inspiration of goodwill rather than an opportunity for manipulations. Thus, the birth of a child with DS does not automatically trigger a need to eliminate the burden of disability, but instead triggers a desire to care and protect the infant with disabilities.
Cyclical, Spiral	Contrary to the linear view of phenomena in the Eurocentric world, the African cultural essence views everything as having cyclical and spiral relationships. This brings harmony as there is no end to anything, but continuous succession from one form to another. The experience of disability is accepted as being deprived in one life or aspect of life while gifted in other aspects or form of life. One form of physical life produces a different form of spiritual life.
Spiritual concepts	Spirituality is at the center of African life, whilst the Eurocentric worldview promotes an intellectual denial of spirit. Whilst the African clan appreciates the etiology of DS, they also appreciate that the series of causal factors is controlled by a supernatural being for a purpose. The findings show a unanimous perception of the birth of a child with DS as a gift from God.

Spirit and matter joined	The African worldview sees spirit and matter as joined whilst there is separation of spirit and matter in the Eurocentric world. The incidence of DS is to fulfill a particular purpose without which DS would have not occurred. Therefore, the occurrence of DS cannot be separated from the purpose and function. They are linked. The findings revealed a multi-pronged approach by the clan in dealing with the challenge of raising a child with DS. The African clan dealt with the matter at an objective, spiritual and affective level as seen with the use of both western medicines, traditional healing that includes the use of rituals and
Communalistic	The African cultural essence with its communal orientation promotes communalistic tendencies while the Eurocentric approach remains individualistic in its orientation. The clan system is based on an idea of collective consciousness. The members of the clan advance the collective aspirations of the clan and represent the clan at an individual level. Even when dealing with an individual, that individual should be viewed in the broader context of the clan. For example, the challenge of the birth of a child with DS was viewed as a challenge for the whole clan, not just for the biological parents. It was a concern for everyone, grandparents, aunts and uncles.

Cooperation	<p>Finally, the African cultural essence emphasizes cooperation contrary to the heightened levels of competition found in the Eurocentric cultural orientation. Thus, members of the clan are expected to work together as a system. The cooperation amongst clan members does not imply exclusion of other significant external support systems such as doctors and social workers. Both the clan and external systems can work together harmoniously in cooperation without competition. For instance, when one member of the clan raises a child with DS, the other members will pool resources in kind and otherwise to help the affected member, instead of seeing the challenge facing a fellow clan member as an opportunity to sabotage or outperform them. In some clans where the mother of the child with DS was younger, either grandparents or aunts took care of the child and allowed the parents to focus on other children and work. The research findings demonstrated that African clans raising children with DS tend to work together to support the parents of the child with DS.</p>
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**(Adapted from Ani, 1994)**

On the one hand Afrocentric social work, according to Mungai (2015:67), can be defined as a form of social work that has been adapted to the needs and objectives of the African people. According to Schiele (1997:802) the assumptions underpinning Afrocentric social work stems from the fact that in spite of the oppression of Africans and the imposition of Eurocentric cultural values, they have held on to some of the values, psycho-behavioral patterns, and ethos of traditional, African culture. Therefore, it must be borne in mind that because of this oppression and imposition, Africans will vary significantly in the internalization and demonstration of a traditional, African cultural ethos and in their acceptance of and pride in Africa (Sherr, 2006:11). The findings of this study confirm that it can be expected that, in some instances, some African families raising children with DS may not have the knowledge, understanding and even willingness to accept the African cultural thought.

Furthermore, an appreciation of the definition of Afrocentric social work should include acknowledging that Afrocentric social work is both particularistic and universalistic (Schiele, 1997:802). Schiele further advanced that Afrocentric social work is not only concerned with the particular liberation needs of African people but also the spiritual

and moral development of the world. On the one hand, the researcher argues that indeed the spiritual tradition of Africans and the extremely bad state of world affairs and human relationships make it necessary for the entire world to turn to Afrocentricity to bring the world more in line with African values and behaviors. The latter affirm human justice and compassion such as *'ubuntu'*. However, on the other hand, it must be noted that the devastating effects of cultural oppression on African people over the years makes it necessary and urgent that the Afrocentric movement primarily strive to eradicate the effects of cultural oppression on Africans as a matter of priority before considering its relevance to the global world.

### **6.3 The indigenous social work practice guidelines for assisting African clans raising children with DS**

The guidelines are divided into two broad categories. The first category relates to the technical aspects of the social work helping process. This will include, amongst others, the manner in which the African clan can be engaged in the helping process through a clan-centred intervention, issues of respect and secrecy as well as incorporating themes covered in the 5 methods of Afrocentric social work as envisaged by Schiele (1997:811). This includes a focus on transforming people from sub-optimal to optimal thinking, fighting oppression, building community strengths as well as ensuring an affective helping relationship and mutuality. The second category deals with organizational/environmental issues influencing implementation of the practice guidelines. These are organizational factors that require attention as they may either hinder or positively reinforce implementation of the indigenous social work guidelines.

#### **6.3.1 The practice guidelines on Afrocentric social work services with African clans raising children with DS**

This section provides the first category of the practice guidelines related to direct provision of Afrocentric social work services to African clans raising children with DS. Given the significant position of the African clan as a basic building block of society in general and particularly in Africa, the practice guidelines are also designed to be African clan-centred. It must be noted that although recommendations are presented under discrete sub-headings, most of them are interrelated. This is further to support

Sherr (2006:12) in his argument that the acceptance and application of the Afrocentric paradigm does not mean the exclusion of other theoretical paradigms. Instead, it means an additional, fresh and legitimate approach for understanding human behavior, analyzing policy and developing social work interventions.

❖ **Guidelines related to dealing with the African clan raising a child with DS.**

On the basis of the vast diversities that exist in cultural inclinations amongst South Africans and the differences that exist between western and African social work as conceptualised by Schiele (1997:810), the researcher considered it prudent for social workers to adopt the framework of cultural relativity as developed by Brydon (2011:160). This professional stance will enable social workers to approach each African clan with an open mind and allow their holistic assessment outcomes to determine which world view will underpin their intervention. In doing this, the social worker acknowledges that culture as an instrument that drives worldviews is at the centre of how each society responds to social challenges. Thus, as per Brydon's (2011:160) framework for cultural relativity, social workers should determine during the course of assessment whether a particular African clan will be best served along the lines of Afrocentric social work or Eurocentric social work. The following guidelines are proposed in this regard:

- Social workers working with African clans raising children with DS should make an informed professional decision following a thorough assessment as to whether the Eurocentric or the Afrocentric worldview will be appropriate for the intervention, based on the choice of the client. Such a determination will allow the social worker to agree jointly with the client (African clan) over a preferred cultural frame of reference when intervening.
- A personalized intervention plan should be developed in conjunction with the African clan according to its needs, and congruent with its cultural frame of reference. The personalized intervention plan could be done on a separate sheet and added to the file or professional records kept on the social work intervention. This plan will help to coordinate the social work services rendered to the clan throughout the continuum of care related to the child with DS. The personalized intervention plan could also be used as a quality assurance tool to monitor the progress of the African clan. This will also assist in dealing with each clan according to its needs and not generalizing intervention

to all clans raising a child with DS because the manner of addressing the needs within the clan depends on the clan's unique contextual situation.

- Additionally, the personalized intervention plan should take into consideration the African clan's changing needs, situation and circumstances. Therefore, the personalized intervention plan should be regularly updated at the different stages of the intervention process. For instance, if the engagement with the African clan started during the course of the prenatal care, such plan should be monitored and updated as intervention continues into postnatal care. If a diagnostic test is undertaken or a clinical diagnosis is made after birth and the results are found to be positive for DS, the intervention plan should be changed and updated accordingly to address issues related to the confirmed diagnosis of DS. Similarly, if a test is conducted and DS is excluded, the plan should be updated accordingly to talk to the fact that the child does not have DS.

The findings revealed that African clans are not given the necessary psychosocial support by social workers in hospitals. This has been attributed to a number of factors including staff shortage and lack of referral by other professionals within the multi-disciplinary team. Thus, the Afrocentric social work guidelines seek to make it the responsibility of the social worker in health care settings to make sure that individuals and clans at risk as well as those affected by disabling conditions including DS are not missed when psychosocial services are rendered. In trying to render Afrocentric social work, social workers may not focus exclusively on one condition like DS, but should rather group together all manner of conditions that feature chronic disabilities and design a systematic process of identifying and supporting the clans at various stages in the service continuum. This requires close coordination and collaboration with other members of the multi-disciplinary team. Social workers are encouraged to be proactive and take the initiative instead of simply waiting for referrals from other multi-disciplinary team members, in their efforts to provide Afrocentric services. As independent professionals with full appreciation of own expertise and offerings within the health care settings, social workers operating within the Afrocentric orientation should be able to develop a service delivery strategy in line with established processes and systems within the health care setting and not focus on the limitations brought about by the fact that they are operating in a secondary setting.

Opportunities exist for a variety of systems to be developed and implemented for effective service delivery and collaboration within the multi-disciplinary team. The information and communication technology (ICT) platforms such as a referral and case management systems may come in handy to assist in this regard, so that every team member may be alerted as early as during admission or during the course of in-patient medical care when issues arise that call for intervention by a member of the allied health professional such as social workers. This kind of intervention is required to help curb incidences where individuals and clans in need of psychosocial support go through the system without receiving such support from social workers. These ICT capabilities may be upgraded as enhancements on the current hospital Patients Management system or complimentary platforms may be created to link to the main system so that greater collaboration is fostered between various members of the multi-disciplinary team.

#### ❖ **Providing clan-centred social work services**

The notion of centering the social work intervention on the African clan is adapted from the use of 'center' in Afrocentricity as described by Davis, Williams and Akinyela (2010:339) which they explain as simply meaning to view a phenomenon, in this case, the social work intervention from the standpoint of the people (African clan) who are subjects of the intervention. The African family is therefore conceived from the original definition of the traditional African family being a clan or a collective of people either living together or in separate households, connected by blood and perceived to be one family/clan. To provide clan-centred Afrocentric social work services, the following should be applied:

- Social workers should focus on each African clan's needs and requirements looking at their capacities and strengths. The findings showed that the African clan comes with various strengths and assets, but often those are not considered when interventions are made. This includes the reliance on a large kinship network to interpret and deal with the challenges associated with raising a child with DS. The findings of this study further showed that different members of the clan interpret the condition differently without a coordinated process to facilitate the flow of information within the clan. This causes a lot of confusion. The confusion is partly caused by the

lack of acknowledgement of the other sources of knowledge prevalent in the African worldview such as spirituality and affect. Therefore, acknowledging and encouraging the clan to draw deeply from these sources of knowledge will go a long way in addressing the confusion that arises.

- Efforts should be made to understand the African clan's totem and praises as they influence how the clan reacts to any psycho-social challenge. The findings revealed how African clans and their members identify themselves, connect and symbolize certain personal and collective qualities and competencies using the clan name, totem and praises. Therefore, these artifacts represent a set of valuable resources and opportunities that could be pooled and tapped into in a helping process. It has become clear from the findings that sometimes if not properly harnessed, these artifacts may be wrongfully used when members of the clan resorts to dysfunctional ways of coping with the stress of raising a child with DS such as when some fathers rejected their affected children on the basis that their clans have never had children with disabilities before or when their totems are perceived as representing strength and the condition is summed up as representing weakness that does not augur well for their totems.

- The social worker should strive to understand the interaction and relationship patterns within the clan because they have an influence on how the problem at hand is addressed collectively and individually within the clan system. The findings showed that the African clan system allocates positions and capacities to its different members, accompanied by particular rights and responsibilities. The allocation of these positions determines how members of the clan relate and interact with one another. For example, the position of the aunt carries certain powers, responsibilities and privileges as does the position of grandparents, uncle, father and mother, older brothers and sisters. Most African couples depended on either grandparents or aunts for guidance on what to make out of the birth of a child with DS and what ritual or ceremony to perform following the birth of a child with DS. Therefore, the helping process could be enriched when assisting African clans raising children with DS to tap into these established interaction and relationship patterns within the African clan system.

- Efforts should be made by the social worker to understand the spiritual background of the clan including important rituals and ceremonies and their meaning to the clan. This will assist the social worker to understand how the situation is interpreted by the clan. The findings are unanimous when it comes to spirituality amongst African clans raising children with DS. The findings revealed that the African clans perceived the condition of DS on the basis of three factors, that is, etiology, purpose and function. Meaning that they had an interest in understanding what caused DS from a scientific basis or any other form of explanation of cause. However, over and above the mechanical causal factors, they also had inclination towards appreciating the fact that there is a supernatural force behind all things. The incidence of the birth of a child with DS was constantly viewed as the purposeful will of God. It was viewed symbolically as a statement from God. That it was a means towards some good ending only known by God and thus requiring the clan to be grateful and accepting of the condition. Thus, despite the many challenges associated with raising a child with DS, the African clans interviewed were accepting of the condition and grateful for the gift from God. This was contrary to the attitudes of individuals who are western oriented and families who instead explored ways of preventing the incidence of the birth of a child with DS including termination of pregnancy. The African clan system generally expressed distaste of any thought of termination of pregnancy or any invasive procedures of diagnosing or treating DS.

- The social worker should make efforts to understand the traditional protocols and conventions of the African clans. The African clan is anchored on a rich cultural heritage with a series of unwritten protocols and conventions. For instance, respect is deeply ingrained in the African culture in relation to how one interacts with elders. These includes amongst others, the manner in which one addresses elders such as the requirement to call elders by their titles linked to their positions in the genealogical tree. For instance, grandparents must be addressed as grandparents and parents as parents, siblings as brothers and sisters. The elders are always called by their titles followed by their surnames such as 'Gogo Baloyi' (grandmother Baloyi). It is frowned upon as disrespectful and disgraceful in African cultures to call an elder by their name and this extend to older siblings. Another important aspect of protocol and conventions is the use of non-verbal cues. For instance, the value attached to the issue of maintaining eye contact as perceived in the Eurocentric world is viewed differently in

the African worldview. Maintaining eye contact is perceived to be disrespectful within the African worldview. Furthermore, the manner in which one speaks and dresses also requires serious consideration within the African worldview. All these factors, if observed and respected, may go a long way in facilitating the establishment of a conducive environment for a proper working relationship required in social work interventions.

**❖ Dignity, respect, courtesy and privacy (Secrecy) as values within the African clans**

The entire African clan system including elders, men, women and children should always be treated with kindness, respect and dignity by social workers. The social worker should consider the biological parents' views; however s/he should avoid focusing solely on the biological parents of the child with DS. In the same vein, the views, beliefs and values of the African clan in relation to their child with DS should be sought and respected at all times. The findings of this study revealed that even though the biological parent/s are provided with counselling about raising a child with DS, eventually the child belongs to the whole clan and various members of the clan in different positions influence how the child is raised and the management of DS as a medical condition affecting the child and the entire clan. For instance, some of the clans interviewed followed a process of consultations with senior members of the clan culminating in them conducting a ritual or ceremony. While in other cases the connection between clan relations and the entire clan system was not as strong, the biological parents managed the condition on their own. Thus, the social worker should be able to establish the state of relations and the connection between the child's biological parents and the entire clan system. In some instances, particularly where the biological parents of the child with DS were young, it was found that the grandparents or aunts (in cases where the grandparents of the child with DS were deceased), took over the role of raising the child with DS on behalf of the younger biological parents. The following guidelines are provided:

- In line with the Afrocentric social work principle of mutuality in the helping process between the helper and the helped, it may help to always begin the process by introducing yourself as a social worker and share some personal and family information. For instance, your profession, your family clan/totems/praises and the

reason for the contact with the African clan raising a child with DS. For the social workers coming from a different worldview, they should equally share their own and make explicit the differences as well as possible biases that may arise from such differences, as each person speaks from their own subjectivity regardless of it being known or unknown. The literature on Afrocentric social work underscored the importance of shifting from the notion of professional objectivity, which creates aloofness associated with the Eurocentric worldview, to a more personal and involved helping relationship consistent with the African worldview (Mungai, 2015:66; Sherr, 2006:1; Graham, 2002:17; Schiele, 1997:800).

- It is important to acknowledge and affirm the traditional social support system inherent in the African clan system. The social worker providing services to the African clan raising a child with DS may choose to tap into the role of elders as counsellors and reservoirs of knowledge and wisdom in the African clan system. S/he has to take into consideration the role played by uncles and aunts in supporting couples through social challenges in the context of the African clan system. In this way the services rendered will be seen by the clan as relevant to their situation as all the important role players' contributions are taken into consideration in the helping process.

Where information regarding the clan's spiritual belief system is available, it may help to acknowledge the role of such spirituality on the clan's management of the condition and its impact. The social worker needs to use his/her skills in exploring the meaning of spirituality in the life of each African clan receiving the services.

- It is also crucial to address or call elderly males in the clan/African family by their social titles as *tatana/ntate/tata/baba* (Father) followed by *or/and* with their clan names/surnames/totems which they prefer. In instances where social workers do not have the information, they need to make an effort to find it first, as this will facilitate the process of establishing a trusting relationship. Where possible and known, the social worker may wish to regularly call or refer to their clan praises as the conversation continues. This is important as affirmation of an existing and functional social structure embedded within the African clan system that exerts influence on the manner in which the clan deals with social issues affecting it. This social structure and system exists at an existential level and may be easily ignored when operating at a professional level. However, ignoring the social structure and the clan system, including the values upheld

by the clan does not translate to neutralizing the clan and its facets. The findings of this study reveal that the clan system and its structures continues to exert influence in the existential realm and has the power to reduce professional intervention to a mere formality that lacks real impact on the lived experiences of the people being helped.

- In the same spirit, the social worker needs to address older females within the African clan raising a child with DS by their social titles as manana/mme/mama or aunti (mothers/aunts) followed by surnames or as mothers to their children if the social worker knows the names of the children. If the information is not available, the social worker has to use his/her skills to find this important information with the aim of demonstrating respect an acceptance of the elders as part of the helping process.

- Similarly, social workers need to address or call others in the clan by their social titles and surnames or as uncles or aunts/fathers/mothers to children if s/he knows the names of the children. Similarly if the information is not available, the social worker has to find out, to ensure that the helping process is facilitated in the manner that encourage the members of the clan to feel appreciated hence increase the willingness to participate actively.

- It may be beneficial to address or call children in the African clan raising a child with DS by their traditional names if known. If unknown, it is important to find out. The findings revealed that children are usually given English/Christian names to accommodate the Eurocentric domination, but usually have another traditional African name in line with the naming practices prevalent in their specific ethnic group. Some of the names mirror particular experiences in the clan while others are spiritual, symbolizing succession and continuity from one generation to another. For instance, in some ethnicities, newborns are given names of the deceased to symbolize that they carry the spirit of the departed. Therefore, such information is crucial as it carries with it deep seated sentiments that cannot be ignored and may be important therapeutically for the clan. All these practices signify various genuine phenomenological experiences of dealing with social challenges and if ignored the African clan could be left behind and the social worker move alone in the helping process. In this instance the African clans will not benefit from the helping process as it will not be talking to their lived experiences.

- The African clan raising a child with DS is likely to feel respected when addressed appropriately in line with its clan identity, totems and praises. The social worker needs to engage the African clan politely in accordance with established traditional protocols. For instance, the use of minimal eye contact, bowing to show respect and allowing them to guide you through the interaction, will show the members of the clan that the social worker accepts and respects them as they are. This is how the African clan system operates at an existential level. The findings of this study show that there are established protocols and conventions on social interactions between various sub-systems in the broader African clan system. For instance, children are expected to address elders in a particular way that shows respect for the elders. Kneeling and bowing are some of the mannerisms that display respect. Looking a person in the eyes is generally perceived as disrespectful. There is a different seating arrangement for males and females. For instance, in deep rural areas, women generally prefer seating on the floor whilst men generally do not seat on the floor but use chairs. The social worker needs to be sensitive to this and ensure that no member of the clan feels left out in the helping process through showing understanding of their world view and demonstration of respect for it.

- The social worker may effectively demonstrate respect and value for the clan as a client system by listening with openness to their spiritual belief system and not imposing his/her own belief system. The clan is likely to feel respected when their views and values are considered and when they are involved in decisions that impact their spirituality. Spirituality has been proven to be a cornerstone of African life. Thus, this aspect must not be ignored when working with African clans raising children with DS. The literature showed that contrary to the Eurocentric worldview characterized by the separation of spirituality and matter, the African worldview illuminates the connection between spirituality and matter, as it has already been indicated earlier in this thesis. Indeed, the findings of this study also confirmed this argument. Meaning that part of the understanding and interpretation of the experience of raising a child with DS is spiritual, which enables the clan to cope with the challenges emanating from raising a child with DS. Therefore, any attempt to separate spirituality from such an experience would certainly prove to be counterproductive and also not responsive to the actual needs of the clan.

**❖ Assisting African clan systems raising children with DS to transform from suboptimal to optimal thinking**

While cognizant of the devastating effects of Eurocentric hegemony and colonialism and acknowledging the power of culturally relevant social work practice, one of the areas of focus and a vital pillar anchoring Afrocentric social work is the facilitation to assist African people to transform from suboptimal to optimal thinking. As eloquently conceptualized within the Afrocentric paradigm, the task of assisting Africans to transform from suboptimal (obsession with materialism and fragmentation) to optimal (holistic) thinking is at the heart of Afrocentric social work (Sherr, 2006:03; Schiele, 1997:805). Thus, Schiele (1997:805) stresses that Afrocentric social work is characterized by a worldview that underscores holistic thinking and spiritual development. Schiele further conceptualizes the idea of holistic thinking as implying viewing the world and people as a spider web, with interconnected parts that are mutually determined and that mutually determine the rhythm and harmony of the whole, as already alluded to earlier. This view of the world enables people to view differences as complementary rather than opposing forces. Indeed, the findings of this study exposed this important quality in the manner in which African clans dealt with the experience of raising children with DS. Most of the clans in this study did not view the presence of disability in their children with DS antagonistically as opposite to those perceived to be able-bodied. The presence of a child with a disability was not viewed as opposite to the birth of a child perceived to be normal, hence none of them expressed a need to eliminate a child with DS through any means possible—including termination of pregnancy. All these experiences were viewed and accepted as complimentary and imbued with deeper meaning and symbolism. This provides vital insight into the phenomenological experiences and strengths of African clans requiring to be noted and built upon.

The manner in which the African clan looks at challenges differs greatly from the conventional one that always pushes towards a need to eliminate the challenge. Instead, the African clan strives to understand, embrace, accept and live with the problem with a level of gratitude and hope that it is a means towards bigger and better things to come. This is deeply spiritual and cannot be understood in the material and objective worldview. However, the existence of many decades of Eurocentric

hegemony and colonialism (epistemicides and valuecides) has left a mark on the African worldview. One such area is undoubtedly the mind—and the cognitive domain—hence the need to support African clans to transform their thinking. To achieve the objective of transforming people from suboptimal to optimal thinking, social workers working with African clans need to capitalize on collaborative working relationships, optimal involvement, partnership, empowerment, engagement with the African clan, as emphasized by the developmental approach. It may be important that when important decisions affecting the African clans raising a child with DS are to be made, the African clan receive detailed information on the illness, treatment options and prognosis as a collective and not only the parents of the child. This should not be done following a top down approach that assumes that the African clan knows nothing, but rather in a collaborative and engaging manner that recognizes the African clan's indigenous knowledge systems. The findings from interviews with social workers show that they are of the view that involving and explaining issues help the African clan to have an idea of what is happening and where they come in. Consequently, this helps activate their involvement, participation and cooperation. The following guidelines are designed to facilitate effective involvement of the African clans raising children with DS during the course of the social work intervention:

- Contrary to Eurocentrism, the African worldview values spirituality, collectivity, mutual aid and cooperation. Thus these values should always be emphasized and African clans helped to develop them further. Social workers operating from an African worldview should be able to discern from the interaction with the Africa clan when elements of material want and other aspects of the limiting western view exist and then accordingly challenge them to shift towards a more Afrocentric view of the world based on a genuine integrative view of the interdependence and interrelations of every aspect of the cosmos.
- In line with the African worldview, social workers have to ensure that during the course of their work with African clans they shift emphasis from the restricted and superficial sense of self and human-worth based exclusively on materialism to the one based on spirituality and affection. It has been adequately demonstrated both in the literature on the Afrocentric paradigm and the findings of this study that, contrary to the Eurocentric worldview, which is exclusively reliant on materialism and objective truth,

the Afrocentric paradigm relies on spirituality and affection as sources of knowledge and power including but not limited to material and objective truth. For instance, from the findings of this study, African clans appreciated the factual and scientific explanation of the cause of DS, but underscored the fact that such causal factors are driven by supernatural powers of the creator for a particular purpose. As such, they did not view the incidence antagonistically as does others from the Eurocentric worldview. Therefore, it is crucial that when assisting African clans raising children with DS, the social worker allows the clan to tap deeply into all their existential sources of knowledge and power.

- To facilitate the above, it is essential to create a conducive environment for effective engagement on issues of spirituality and affection, taking into account issues of privacy and confidentiality.
- Social workers have to suspend own judgements, particularly when they may not necessarily share a similar worldview. This will also show that the social worker apply the non-judgemental attitude as one of the existing social work value.
- The importance of involving the African clan throughout the process of intervention cannot be over-emphasised. It is important to facilitate and support the members of the African clan to reflect on their experiences in relation to raising a child with DS. Recognition of these experiences may assist in facilitating the helping process as the members of the clan will see the social worker as someone who is willing to accept them as people whose experiences are important hence increase participation.
- The social worker needs to document the African clan's perspective with regard to what the clan as a collective would like to achieve, noting their strengths and weaknesses and use the strengths perspective to maximize these identified strengths.
- The social worker needs to ask questions to clarify aspirations, wishes, needs, preferences and concerns from the members of the African clan.

- The social worker has to find out from the African clan regarding its members that would like to be involved and the extent to which they have to be involved in the intervention process. This refers to significant members of the clan occupying particular positions of authority as per customary practices and the African clan's wishes. Most African clans would want the paternal elders to shoulder the responsibility of decision making on behalf of the entire clan. However, it should be noted that every member of the clan represents the collective consciousness of the clan and may not be viewed individually even when expressing deviant views, such must be considered in the context of the clan system and how the clan would like the intervention process to unfold.
- It is therefore important to fully engage members of the clan present at sessions, recognising their important role in the intervention process, as representing the aspirations of the clan.
- Social workers need to ask if the manner and style in which they communicate is effective for the African clan and the presenting situation as they proceed to ensure that they move at the same pace with the clan.

❖ **Assisting African clans raising children with DS to fight against political, economic and cultural oppression**

From an Afrocentric social work perspective, cultural oppression is the foundation of political and economic oppression (Sherr, 2006:03; Schiele, 1997:805). Thus, social work should in line with Brydon's (2011:160) proposal, advocate for cultural pluralism. Cultural pluralism is the belief in the equal affirmation and contribution of the various groups that constitute a multicultural society (Schiele, 1997:805). Social workers need to play a vital role in educating and affirming the African clan's knowledge systems, historical experiences and advances. The fight against political, economic and cultural oppression is consistent with the developmental approach adopted by the South African government and the broader social work fraternity as conceptualized by Patel (2008:73). In line with this, Patel (2008:73) contextualized the developmental approach enshrined in the White Paper for Social Welfare (DSW & PD, 1997) as "a pro-poor strategy promoting participation of the socially excluded...to achieve social and

economic justice, human rights, social solidarity and active citizenship". Furthermore, Patel (2008:73) underscored in her conceptualization of the developmental approach, the harmonization of socio-economic development. Thus, over and above helping the African clan deal with the immediate psychosocial challenges associated with raising a child with DS, the social worker should also aim at empowering the African clan politically, economically and culturally for genuine emancipation and empowerment to occur. Communicating effectively with the African clan is the springboard of achieving political, economic and cultural emancipation through Afrocentric social work interventions. The manner in which a social worker communicates with the African clan is as equally important as the information being conveyed. African clans that understand the social worker are more likely to accept the intervention, understand their role in such intervention processes, own and control the change brought about by the intervention. The following are some guidelines on how to achieve this:

- The social worker needs to dedicate adequate time to a discussion of the clan's historical experiences and achievements and sources of pride.
- The social worker has to also identify and build on the clan's strengths.
- The social worker should always be aware of the influence of his/her non-verbal cues, body language and its subconscious meaning.
- Equally essential is the social worker's awareness of the verbal/communication barriers. S/he has to enquire from the African clan the language they are comfortable with when communicating with them.
- The social worker needs to encourage the members of the African clan to share their knowledge and skills.
- It is also important for the social worker to pay attention to the African clan's ways of being, knowledge and power. This requires active listening in order to hear and understand what is being said, meant and implied.

- Finally, it will be fruitful to build on the African clan's strengths and capabilities. Based on the social worker's assessment of the strengths and capabilities of the African clan, the clan may be pointed towards articles, websites and books that might be helpful for further understanding of the condition. The Down Syndrome Association (DSA) have numerous leaflets and booklets containing very useful information that may be used by the clan to understand the condition DS better and its management. The social worker may even develop personalised information packages for the African clans on DS.

#### ❖ **Building on the strengths and assets of the African clan**

African clans that raise children with DS, although often devastated and shattered by the experience, always have strengths and assets that require to be tapped into by social workers assisting them in order to ensure sustainable change. Any intervention that ignores these strengths and assets run a risk of bringing change that may be alienating and unsustainable. Afrocentric social work is underpinned by a belief that each community, even oppressed ones, possesses elements that have and can be used to elevate their status (Schiele, 1997:809). These elements are skills, knowledge systems, cultural practices and belief systems, resources (human and material) and talents that the African clan holds in addition to their spirit of survival and resilience. Thus, the importance of these strengths in the helping relationship and interaction between social workers and African clans raising children with DS cannot be over emphasised. To promote an effective and efficient helping relationship that builds on the strengths and assets of the African clan, the following guidelines were formulated:

- Although lack of hope may sometime characterize some of the African clans raising children with DS, their inherent strengths and assets need to be explored, acknowledged and used as a starting point for any professional intervention. This is in line with what is emphasized by the strengths perspective that the strengths of the clients have to be maximized at all times in the helping process. They need to be fully integrated into the service delivery system.
- It will be beneficial to ensure that the cultural and traditional systems (practices, rituals and ceremonies) and structures (institutions/organizations) indigenous to the

African clan are frequently explored and used by social workers and their employer organizations to better meet the actual needs of the African clan.

- It may also be vital to ensure that the indigenous systems and structures are viewed as partners by social workers. Such acknowledgement of the indigenous systems and structures as partners may translate into their perspectives about serving the African clan being deemed just as legitimate or even more than those of the professional organization of social work.

- The social worker has to take into account the fact that the African clan raising a child with DS has the right to self-determination. This requires acknowledgement by social workers of the key role players, their positions of power, influence and control over the values and interests of the African clan. The social worker may be able to speak to the values and interests of the clan and integrate those values that promote the African clan's interests into the professional helping process. By so doing, the social worker may effectively empower the African clan systems by supporting their self-help efforts.

- The social worker has to further demonstrate a friendly attitude towards the African clan system as a whole. The way the social worker addresses the African clan in line with its clan name, totems and praises may go a long way in creating a conducive and enabling environment for members of the clan and their sense of self-determination. This means that the social worker has to make an effort to know these elements and incorporate them in the helping process.

- The social worker has to make efforts to understand the African clan's background. The African clan may be more comfortable with an affective and personal trusting relationship, given the nature of the African worldview as discussed earlier. The literature showed—and this has been confirmed by the empirical findings—that the African clan system is likely to prefer that their professional helpers know them personally. So, the social worker needs to support them to open-up through being personally involved with them. It is helpful that the social worker focusses on the wellbeing of the clan as a whole rather than being concerned with the diagnosis of DS

on the child and its impact on the clan. The social worker needs to focus on building a good relationship with every member of the clan.

- The social worker needs to work on trying to understand the African clan on its own terms and avoid making assumptions. This can only be attained by maintaining an open relationship with the clan and demonstrating respect for the way of doing things of the clan as a unit.

**❖ An affective helping process and mutuality within the professional relationship**

On the one hand, an affective helping process implies that both the social worker and the African clan are emotionally connected (Schiele, 1997:810). The African clan system seems to shun aloofness and objectivity and instead prefers affective connection with the helper. The objective helping process prevalent in the western form of social work characterized by emotional distance is generally viewed as undesirable. Emotional distance in the form of objectivity seems to prevent the complete development of a trusting, authentic helping relationship with the African clan system. Similarly, objectivity is viewed as an illusion within an Afrocentric framework because objectivity itself is a value that assumes that there is, outside of both the worker and client, an absolute "truth" or reality about the client's problem that is best discerned and evaluated by the worker (Schiele, 1997:811). It is against this backdrop that Afrocentric social work puts emphasis on emotional connection between the helper and the helped that equally acknowledges the viewpoints of both in defining and understanding the problem at hand. In the mainstream, this is discouraged in social work and dismissed as professional heresy or deprofessionalization (Schiele, 1997:811).

Mutuality within the professional relationship means that both the social worker and the African clan can learn from each other and the lives of both are affected by a similar worldview (Eurocentrism) that has had adverse implications for all (Schiele, 1997). This affirms that the African clans have strengths and assets that can be used to fortify and educate the social worker. This kind of mutuality also allows the social worker to understand that the African clan's problem is not just a problem for the clan but is also a problem for the social worker too. The African clan's problems directly or indirectly

affect the social worker because both are exposed to the Eurocentric worldview that nurtures the kind of suboptimal thinking and value orientation discussed earlier. The oppression, anxiety, estrangement and conflict that result from this worldview have manifold manifestations and expressions. The point here is that although the social worker may be a professional, benefiting from the status of being a professional, s/he is not immune from the ravages and dilemmas of the Eurocentric worldview. The following are provided as guidelines:

- The social worker needs to make time for emotional connection with the African clan through the balanced use of both empathy and sympathy. The exclusive use of empathy in the Eurocentric paradigm militates against the common use of sympathy in the African worldview. Thus empathy may be interpreted as being aloof and uncaring resulting in failure to build genuine rapport.
- The social worker may choose to share freely their emotional reactions to the presenting problem without reservation. They may cry with the clan if need be, share their anger, frustrations etc. It may be difficult to achieve the above where there is shortage of staff and unbearable workloads. Therefore, proper and adequate staffing may need to be addressed before social workers attempt to fully implement this guideline.
- The social worker may share their views, thoughts and perceptions regarding the impact of Eurocentrism on their own life and everyone else affected and relates it to the presenting problem. This should be done carefully in a balanced manner that allows the African clan to share and avoid taking over the process. This will of course mean that they will need more time with the clan. As indicated earlier, social workers may consider addressing issues of adequate staffing before embarking on this guideline.
- It is vital to allocate adequate time with the clan and build lasting relationships, instead of the short-term view prevalent in mainstream social work practice.

**❖ Shared decision-making process with regard to the management of DS within the healthcare system in South Africa.**

Shared decision-making process involves providing the African clans raising children with DS with reliable information on the likely benefits and harms of interventions or actions, including any uncertainties and risks. Furthermore, it involves checking and affirming the preferences of the clan when a decision is taken and supporting them through implementation of such decisions. The social worker in this context brings to the table expertise and information regarding various options available for professional assistance such as details on socializing and caring for the child, feeding, selecting a special school, as well as available social grants. The social worker may also be in a position to discuss the prognosis of the condition and treatment options as communicated by the medical team. On the other hand, a clan as a client comes along with knowledge on how the condition impacts its daily life, its meaning to the clan, its personal attitude to risk, values and preferences. This study revealed numerous themes that the African clans raising children with DS raised as challenging areas of decision making that they struggled with. Thus, their inclusion in the guidelines provides an evidence-based approach to dealing with the themes going forward. The themes that emerged relate firstly to how the social worker may approach the issues of shared decision-making with the client during the course of the helping relationship so that there is a reasonable level of understanding and appreciation of this valued theme. Often, as seen with the experiences of the African clans raising children with DS, the issue of shared decision-making is overlooked and at times dismissed as unimportant by both parties, despite it having a strong bearing on what happens later. This was followed by addressing informed choices and consent; the legal implications and complications surrounding some decisions; as well as a list of common areas of decision making associated with raising a child with DS. The following are guidelines on specific themes that may be covered by the social worker:

➤ ***Shared decision-making process within the professional relationship***

- It may help the working relationship with the African clan raising a child with DS for the social worker to check with the clan as to who ought to be present when major decisions such as those relating to elective surgery and institutional care are made. This is to ensure that the process is consistent with the clan's traditional protocols and conventions.

- It is essential for the social worker to ensure that his/her communication styles and approaches are appropriate and effective in the context of the clan. S/he may choose to discuss the possible advantages and disadvantages of certain options in simple language that the African clan is comfortable with.
- While trying to ensure the best possible communication style and medium of communication appropriate, the social worker needs to also consider following the African clan's leads and preferences for participating in the discussions. This is based on the view that the African clan has something to contribute to the list of options and they must not be barred from sharing such and having an opportunity to view all options in perspective in the bigger scheme of things. This means that the social worker needs to discuss how the desire of the family to raise their child with DS at home and perform some cultural rituals on a regular basis ties in with the need for particular medical and therapeutic interventions and perhaps the need for a special school which might turn out to be a distanced boarding school. All these aspects will have to work together and it may not help anyone to dismiss or ignore any of them.
- It is crucial that the social worker avoids at all costs focusing exclusively on the medical condition. This may dampen the working relationship and overshadow many other positive aspects of the situation surrounding the clan. Thus, the social worker may find it beneficial to engage the African clan raising a child with DS on various aspects of interest to the clan and their lived experiences such as values and spirituality and how they impact on the manner in which the clan manages the condition. The ability of the social worker to consider all these issues throughout the different stages of the helping process will reinvigorate and usher in positive energy to move the process forward. Through tapping into other positive aspects of the clan's life, particularly aspects that the African clan feels strongly about, may change or be modified with time depending on new experiences.
- The above may take more than normal time to unfold; therefore, the social worker needs to plan a longer term intervention to cater for all these dynamics and avoid rushing the process. The social worker may also need to be flexible enough to defer some of the decisions to later sessions, depending on the needs of the clan.

- The social worker may at times find that the African clan does not have enough knowledge to make the decision or find it difficult to decide on some issues. For instance if the social worker is seeing the mother who may not readily have details of what sort of family rituals need to be performed or not in a position to make a decision regarding treatment options for the child with DS. The social worker may request that they bring in additional members of the clan who are in a position to share more detailed information and be able to make decisions.
- As indicated earlier, some decisions may infringe on the rights of the biological parents of the child with DS. Therefore, it is important that the social worker remains mindful of the constitutional rights and responsibilities of the mother and the father. They legally have the right to say no and to refuse advice from the social worker.

It must be noted by social workers that in some exceptional situations where decisions have to be made per court order, the social worker is required to follow the constitutional rules and regulations. For example, if a decision needs to be made about an unborn baby with a high risk of DS or an instance where a diagnosis is made prenatally and there are differences in opinions between parties involved within the clan. Among other factors, the biological parents or clan members may have different and at times conflicting views regarding the desirable path to follow once a high risk has been determined or a diagnosis made of DS. As found in this study, the medical fraternity routinely give termination of pregnancy as an option or even serious surgical interventions such as heart surgery which some among the clan or between the biological parents may strongly oppose. For instance, the mother may as it is legally permissible by law, opt for termination of pregnancy when the father wishes for the pregnancy to proceed. The father or the mother may approach a court of law for an order and if such order is granted, it must be respected by all including social workers involved with the clan. The findings of this study also found that most African clans had issues with institutional care and special schools, particularly boarding schools that are located far from where the clan resides. It has proven anomalous that social workers and other professionals insisted on and consistently persuaded the clans to use them. The African clan perceived such action as outsourcing their God-given responsibility to care for their children, particularly children in need of constant care like those with DS.

Those that ended up giving in to the pressure to opt for institutional care could not sustain the decision and eventually pulled out their children from such facilities. Thus, it is important that the social worker listens with a third ear to hear what the African clan implies in line with their values and worldview. Sometimes, the biological mother may see the option of institutional care as best, but had to deal with the constant negative feedback from the rest of the clan about the undesirability of such an option. The clan has a strong influence and that cannot be ignored as it affects sustainability of decisions taken.

#### ❖ **Informed choice**

Whatever decision that the clan makes eventually, it must be on the basis of an all-rounded and adequate information required to make such decisions. Thus, informed choice and promotion of shared decision-making mandates that the African clan give and receive accurate, complete information in the context of a non-authoritarian, two-way relationship with its active involvement. Special attention must be paid to the need for this to reflect both objective and subjective information related to spirituality and affect. At times, the African clan may believe that they do not have enough knowledge to choose interventions even when offered the opportunity to do so due to the devastating effects of colonization and apartheid which inferiorised them as incapable of making own decisions. Despite being deeply spiritual people, the African clan may not see the place of their spirituality in their discussion with the social worker and may on their own accord, suppress own values and belief system. The social worker therefore has a moral and spiritual duty to reawaken the African clan and affirm its sense of self-determination in keeping with the traditional values of social work.

At times, as always done by professionals, social workers may give excuses and advance reasons to justify why the African clan could not be given a choice such as the fact that they cannot read or write or that the members of the clan are not really interested in knowing the options and making their choices. It was revealed from the collected data that at times social workers are driven by what they objectively view as the best interest of the child or the mother and use that as an excuse to ignore the prerogative for informed choice owed to the clan. This is because, social workers are limited as they draw their knowledge solely from an objective source while the African clan relies on numerous other sources of knowledge and insight that have been proven

in literature to be equally valid and essential. Most importantly, these sources of knowledge form part of their phenomenological experience or existential conditions and therefore cannot be ignored. Some social workers reported that the African clan may present alternative options that are less known in the professional realm and may be perceived as risky by the social workers. For example, one social worker reported that most African clans preferred to keep their children at home and use traditional African herbs and other rituals to manage the condition and they were open to letting their children receive any medical treatment available. Therefore, the need to have a discussion on these issues could not be established. They reported that those that were opposed to some medical treatment were not interested in hearing what the medical explanation was and would therefore not benefit from discussing such issues. The above scenario, if left unattended, will wittingly perpetuate myths and condemn Africans to a state of permanent detachment with their reality. This is because all these aspects work together and affect them directly and must be viewed in that context. The DS treatment and management options do not in any way conflict with the other sources of knowledge, but are complimentary. Therefore, the social worker may create sustainable harmony by fully embracing the Afrocentric philosophy that says all things are connected in a reciprocal, complimentary and interdependent relationship. The belief that God blessed the family with a child with DS, does not dispute the scientific explanation of how DS come to be what it is, it instead illuminates the manner in which God brought the condition to light.

In some instances, the social worker does not have all the information. This calls for mutuality where the social worker may be open to learn from the African clan and allow them to bring him/her up to speed with their knowledge systems so that choices flowing out of the African clan's indigenous knowledge systems are also considered as equally valid to those found in the professional realm. However, it must be noted that even in the midst of scarcity of knowledge and information, the principle of informed choice can still be practiced. This means that even when the African clan lacks the knowledge and understanding required to appreciate certain options, efforts must be made to empower them with information and such information must be evaluated jointly with the clan and the social worker to determine its worth for their situation. As per the norm, in some exceptional situations where decisions have to be made per court order, the social

worker will be required to follow the institutional rules and regulations. The considerations to promote informed choice may include, among others, the following:

- On the basis of the empirical findings, the African clans raising children with DS want to know the options and the choices available to them regarding their child with DS. The ultimate choices will have to stem out of all available sources of information including objective and subjective sources. The social worker needs to encourage the clan to decide how best to manage this particularly in relation to who must be involved in line with their cultural orientation. The social worker needs to leave the decision to the clan and respect whatever their decision. Where the clan struggles due to lack of information, the social worker has to work with them through the information. The empirical findings show that the African clan requires information and support to decide on the following:

- Medical treatment and care options (thyroid treatment)
- Surgery (Cardiac/heart operation)
- Therapeutic interventions (physio and occupational therapy, speech therapy)
- Placing a child in a normal or special school
- Day or boarding school
- Home-based care
- Family involvement
- Community involvement
- Participation in a support group
- Use of other support (spiritual and traditional medicine)

Therefore, the social worker has to address the need for information in any of the above areas and share it with the African clan. Such important information enables the African clan to make informed choices which eventually get incorporated into the personalized care plan for the clan. The personalized care plan should therefore clearly indicate their choices regarding the aspects of care.

**❖ The role of the biological parents in the Afrocentric social work intervention.**

The social worker should remember that the African clan does not imply that everyone in the clan must be there, but rather that any member of the clan system speaks and acts in a manner that is consistent with the clan. Contrary to the separatist and/or fragmented view of reality, the African worldview promotes unity/oneness and interconnectedness between everything including its clan members. The same principle applies even in instances where the African mother is seen alone. Sometimes, due to socio-economic challenges and geographic location that is often far from health facilities, the African clan may not always be able to avail all significant members of the clan that it would normally prefer to preside over issues such as the ones discussed during these sessions. Thus, whoever is available should be engaged in a manner that embraces the clan in an African clan-centred manner. The biological mother in the context of African clans raising children with DS is the first point of contact with professionals, particularly in health care settings. Thus, the biological mother should be appropriately and accordingly engaged throughout the process starting with high-risk pregnancies through to child birth and lastly to postnatal care.

To make the involvement process effective, the following guidelines should be used in relation to the biological mother and where applicable the father too:

- The social worker has to explore ways of ensuring that the biological parents are involved in deciding the goal of the social work intervention. Given that the biological parents have the rights and responsibilities over the child, it is important that they are not left out of the helping process. The findings of this study showed that in some cases, the biological parents are not directly involved in raising the child with DS due to a number of considerations by the clan such as their age and work commitments. Often, where such considerations are made and elder members of the clan take over, the biological parents do not get involved and often decisions are imposed by professionals on the clan based on what professionals consider the best interest of the child. This is often caused by the fact that the elderly caregivers may be illiterate or ignorant of the rights and responsibilities that they have as guardians on decision making. Thus, it may be fruitful for the social worker to play an advocacy role on behalf of the biological parents and guardians in ensuring that they are involved when decisions are made with regard to the treatment process.

- The social worker may also look into ensuring that the biological parents are truthful about the information they provide to support their care. Sometimes there is no real reason for the exclusion of the biological parents other than the elders being protective of their children and not prepared to expose them to dealing with the challenge of raising a child with DS. In some instances as shown in the findings, the biological parents may not be married as per customary requirements for them to be recognized as a couple with customary rights and responsibilities over the child. Often, the elders and the younger parents are skeptical to bring these issues to the attention of the social workers or any other professionals providing services to them due to their thinking that the professionals may not understand the customary precepts. So they opt to hide the information. This is partly due to the fact that the African cultural heritage is inferiorised in the eyes of the Eurocentric worldview, which is seen as occupying a superior position in the cultural hierarchy. Thus, it may be helpful for social workers to assist in demystifying these myths and restoring the pride in the African heritage so that the African clans are free to express themselves in line with their cultural orientations without fear.

- The social worker has to explore ways of assisting the biological parents and be open to learning and actively participate in decision-making and provide feedback about the services provided to the clan. Once the biological parents open up, they must be assisted through the process to use the information shared to add value to the helping process and grow out of the process of engagement. It should be an empowering experience where the biological parents are enabled to assume their rightful position as parents and take full responsibility of their roles as mandated by their cultural heritage. This will go a long way in addressing the developmental gap created when elders simply take over and leave the biological parents of a child with DS outside the process of raising the child.

#### ❖ **Pregnancy and child-birth**

The pregnancy period marks the beginning of the process culminating in child-birth. It is important that social workers in health care settings identify and begin working with the potential mothers during pregnancy. A reliable referral system should be developed for the African mothers identified as high-risk such as those of advanced maternal age

(AMA) and those with previous history of DS to be prioritized for psychosocial support. As indicated earlier, Afrocentric social work services should always be clan-centred and recognise the need to support the mind, body, soul and spirit of the African mother and their clans during the trying periods of pregnancy and birth. The kind of support required at a particular time will depend on the status of the African mother. Beginning contact during pregnancy is beneficial as it allows adequate time for the social worker to get to know the pregnant mother and her clan as well as go through all the important information in time. Therefore, this should be looked at from the perspective of the need for adequate time with client systems as well as the advantage associated with early interventions. According to the DSD's (2013:27) Framework for Social Welfare Services (FSWS), early intervention services focus on the early identification of risks, behavior and symptoms in individuals, groups and organisations that could negatively impact on social well-being. Furthermore, the FSWS stresses that services at this level are aimed at limiting the impact of the risk and preventing the development/progression of social problems.

The following guidelines are provided to assist the African mother in this regard:

- The social worker has to encourage the mothers to discuss social issues that affect their well-being while going through pregnancy. Building a personal relationship with the African mother as propounded in the framework for Afrocentric social work, where mutuality in the helping relationship is seen to enable the client to open-up to the social worker. This involves focusing on the mother holistically in her social environment and cosmos. The discussion should not centre on the pregnancy, but consider the pregnancy in the context of all other important social events surrounding the mother such as the clan system, the community, the physical environment, belief system and values. The social worker should be able to also share their own experiences in relation to what is discussed with the mother. This is consistent with the technique of purposeful self-disclosure, but particularly important in Afrocentric social work as it gives practical effect to the notion of mutuality in the helping process. This differs from the reductionist focus of the Eurocentric social work on the objective view of the presenting problem and ways of addressing it. The Afrocentric social work approach is holistic and focuses on the bigger picture.

- As will be expected in the African worldview, the mother is viewed in the context of the clan and at times the social worker may need to involve other members of the clan through the guidance of the mother when issues arise that affect the clan system. For instance, when the mother relates issues around the marital relationship or clan functioning, it will be helpful to seek the permission of the mother to sanction the involvement of significant other members of the clan. This may also include the involvement of other care providers within the multi-disciplinary team.
  
- The social worker needs to support the African mothers to realise their spiritual needs even when admitted for a medical condition. For example, traditional healers/diviners, pastors and other spiritual heads within the African-centred worldview could be allowed to offer prayers to the African mother, if required. The health care facility/space should be transformed to be able to accommodate arrangements for such services.
  
- It may be helpful to also consider allowing and encouraging African mothers to use religious artifacts such as beads and anointed water/oil that do not hinder the provision of medical care.

It has been advanced by Jomeen and Martin (2008:393) that women usually have moods and emotions, and worry about issues during pregnancy and birth. This situation calls for social workers in health care settings and all relevant allied health professionals to recognize these moods and emotions and then offer the much needed psychosocial support, guided by the assessment outcomes. Some of the strategies that could be used to assist African mothers include the following:

- An enabling and conducive environment for the African mother to feel free to approach and discuss any fears, worries and issues including spiritual aspects that form such an important part when offering Afrocentric social work services. This may be achieved through building a personal relationship with the mother wherein both the social worker and the mother share personal information about their lives including how the medical condition affect them. The social worker may also share his/her own feelings about the condition as a human being and relate personal experiences. As indicated earlier, self-disclosure is purposeful and in this case it may be a way of

normalizing the client's experiences and also encouraging the client to share without any fear of being judged.

- Moving from the holistic, integrated and unifying principle of Afrocentric social work, African mothers should be regularly asked about their experiences within the health care facility regarding the care and services that they are receiving and how they affect them. This may be addressed in the context of the broader social experiences related to their cultural heritage, spirituality and clan. The discussion may look at the various intersections, relationships and interdependence between all aspects of the mother's cosmos.

### **6.3.2 Organizational factors that promote implementation of Afrocentric social work services**

In addition to the discussion on technical guidelines for assisting African families raising children with DS, it is imperative that the organizational environment where these Afrocentric social work services are rendered is receptive and responsive to the services. Thus, the following section focuses on organizational issues that need consideration in promoting implementation of Afrocentric social work both in health care settings and community service points. Thus, it is important that a well-coordinated and well-integrated Afrocentric social work service delivery system and environment is created to support the efforts of social workers who make an effort to practice Afrocentric social work in assisting African clans raising children with DS. Leadership and commitment from top management and department heads will play a major role in institutionalizing Afrocentric social work services as well as creating systems to measure and provide feedback to the staff and clients about the impact of such services. Therefore, the consideration of contextual factors is imperative in supporting implementation of Afrocentric social work services. It must be noted that these set of organizational guidelines are purely based on a theoretical and perceived considerations of the required organizational environment for the implementation of the technical guidelines discussed earlier on. They are not based on the findings of this study as it did not have an organizational component. The following are some suggested ways to address the organizational issues.

## ➤ Leadership

The availability of suitable leadership that shares the vision for Afrocentric social work services is crucial for the successful implementation of these services. As indicated, the rolling out of Afrocentric social work services to the African clans raising children with DS will require a serious re-arrangement of services, additional resources and time. Thus, good leadership is required to authorize such changes and support the process of implementation. Leadership in this context refers to a collective of people with authority to make important decisions in organizations rendering social work services to the African clans raising children with DS from top management, departmental and unit heads, supervisors and other senior staff members in the health care settings and community service points. As noted by Frampton, Guastello, Brandy, Horowitz, Smith, and Stone (2008:41), leaders in their own behaviors and values, set the tone for implementation of client-centred care. It is the prerogative of leadership to ensure that staff members have the resources and flexibility they need to provide Afrocentric social work services.

The following are proposed:

- It is important that, where possible, a clear strategic vision and promotion of a climate conducive for experimentation and risk taking is encouraged in facilities providing Afrocentric social work such as health care settings or community social services. It is through the creation of such an environment as described above that social workers may be able to contemplate implementation of the proposed Afrocentric guidelines for assisting African clans raising children with DS.
- Service-point/facility managers may need to re-examine organizational policies and rules to encourage the implementation of the principles of clan-centred Afrocentric social work services. This may be facilitated by conducting service point/health facility readiness assessment to identify the aspects on which to focus.
- Where functional quality assurance teams or committees exist, such should be roped in to assist in the implementation and evaluation of the impact of clan-centred Afrocentric social work services. However, social workers practicing Afrocentric social

work should themselves stand as institutional champions or focal persons to help precipitate interest and formation of positive attitudes for behavioral change. New initiatives require leaders who will transform an idea into a lived reality. Further to clarify this, McCormack, Dewing and McCance (2002:28) are of the opinion that the champions can serve as vital linkages to senior management, sharing information, influencing others and fostering synergy with broader organisational goals.

- It is imperative for the leadership to help inspire action among the multiple players needed to advance clan-centred Afrocentric social work services through demonstration of open commitment and serving as role models.

#### ➤ **Staffing**

Human resources remain essential assets and crucial ingredients in delivering clan-centred Afrocentric social work services. This is because without adequate supply of staff members, it may be impossible to realize the dream of rendering Afrocentric social work services to African clans raising children with DS. Thus, adequate staffing of social workers is crucial to the success of any attempt at implementing Afrocentric social work services given that it takes much longer to render Afrocentric social work than the conventional social work services. It is common knowledge, however, that the social work sector has over the years been grappling with inadequate numbers and unbalanced skill mix and mal-distribution of staff (Earl, 2008:36). Service point/health facility managers, in collaboration with statutory bodies and professional associations of social work in South Africa, may collaborate and explore the best ways of institutionalizing Afrocentric social work services for African clans. They may also explore the possibility of engaging retired/veteran social workers who are passionate about Afrocentric social work as volunteers to assist with implementation. The above predicament facing social work shortages occurs in the context of a state of affairs of social workers who have completed their training but cannot be employed whereas there is a serious shortage of social workers in the field. This is coupled with the efforts of the government to train social workers without any plans to place them in positions where they are needed.

## ➤ **Education, training and staff development**

Competent Afrocentric social workers are required to deliver a quality service that is responsive to the needs, preferences and expectations of the African clan system. The education and training of social workers on Afrocentric social work is thus imperative.

Therefore, the following guidelines are provided in this regard:

- The managers in charge of social work services to African clans raising children with DS may encourage and explore the possibility of in-service training of social workers on the Afrocentric social work approach. Where regular staff development program exists, such may be used to cover regular refresher courses on the Afrocentric paradigm. Where practically and operationally feasible, this may be tailored to the specific job, particularly focusing on social workers attending to African clans raising children with DS to ensure that they receive the training.
- Academic departments offering social work programmes has to explore possibilities of infusing Afrocentric social work into the social work curriculum in South Africa, so that social work graduates could emerge with the necessary knowledge and skills to address the actual needs of the African clients, within the cultural context that is acceptable to the clients. This may call for a review of the social work curriculum. This is already happening in South Africa through the intervention of the Association of South African Social Work Education Institutions (ASASWEI). The ASASWEI national leadership embarked on a programme of decolonisation of social work education as part of its strategic action plan from the academic year 2016 onwards.
- The social work regulatory body in South Africa, the SACSSP, with its mandate of protecting clients and ensuring that clients receive quality and relevant social work services, may have to consider exploring ways of ensuring that social workers that work with African clans are trained in Afrocentric social work. This may be linked to the requirements for renewal of registration.

## ➤ Resources

The guidelines can only be effectively implemented when the necessary resources are made available. Resources are required not only to ease difficulties that staff go through in offering services but also to make clients more comfortable while at the service point or health facility. For example, making communication tools and vehicles available for home visits for all social workers in community service points and health care settings will assist in implementing Afrocentric social work. The leadership or management teams of service points and health care settings may have to carry out an audit of the resources available to determine needs for further action. Social workers working with African clans raising children with DS may require more resources to cover various aspects of care including the need to pitch their intervention at clan level instead of the usual work with individuals and families as conceptualized in the Eurocentric worldview. The intervention may also be expected to last longer than usual given the personal nature and a holistic focus adopted in Afrocentric social work.

## ➤ Infrastructure and environment

The built and aesthetic environment of service points and health facilities is very important to the well-being of both clients and social workers (McCormack et al., 2011:3). The social work clients will most certainly come with heightened feelings of stress, anxiety and vulnerability and that the environment that meets them has the potential to profoundly exacerbate, or conversely, to profoundly lessen these states of mind (Frampton et al., 2008:170). Creating a more humane and home-like environment with Afrocentric items and artifacts can assist clients to maintain a sense of identity and signals that the social worker honors the clients' world. The idea of incorporating Afrocentric artifacts in the environment does not assume that all social work clients are Afrocentric, but rather seek to highlight the significance of transforming the physical spaces from the Eurocentric domination to a new outlook that at least acknowledges the diversity of the clientele. The current situation only reflects a single cultural orientation of the west despite the fact that these are physical spaces in Africa, they carry no reflection of the African cultural heritage. This is grossly unfair and represents a real assault on the African cultural heritage. Therefore, social workers practicing

Afrocentric social work may find it prudent to advocate and strive for the recognition of the African heritage in all manner of decorations and styling of physical spaces used to render services to African clans raising children with DS.

The following guidelines are provided:

- Firstly, a clan-centred environment of care is one that is safe and clean. Thus social workers may wish to work towards more cleaner and safer working spaces for the African clans raising children with DS to feel at home when attending social work sessions. This can be achieved through active advocacy at all levels of government and non-governmental organizational leadership and civil society. The idea may also be taken up through the statutory body as a guardian of the interests of social work clients.
- Where possible, social workers rendering services to African clans raising children with DS may want to make use of African styled buildings, furniture, fixtures, fittings and all manner of interior decorations. This African aesthetic is important for African social work as the profession attempts to decolonize itself and restore pride in the African cultural heritage and undoing of past destructions fueled by colonialism. Social workers with an Afrocentric social work orientation/inclination are well positioned to work on these issues.
- The sitting arrangements and interaction patterns may be changed from the usual Eurocentric configuration to those that reflect the African worldview. For instance, the need to seat up, facing each other, leaning forward and maintaining eye contact as advocated in the Eurocentric worldview may be replaced by a more open seating arrangement that allows adequate space and accommodates various traditional protocols as may be preferred by the African clans such as the common circular seating arrangement or the need for women to seat on the floor if they prefer so.
- Infrastructural design should endeavor to provide adequate space to accommodate the African clan and facilitate their privacy, comfort and dignity. This leads to bigger offices with enough relevant furniture. Offices should not be shared by social workers as this compromises the value of confidentiality.

- Waiting areas should be comfortable and have adequate seats for clients and visitors.

➤ **Re-organization of services**

The state of current social work services requires transformation. As argued earlier, the researcher considered it prudent for social workers to adopt the framework for cultural relativity as developed by Brydon (2011:160). This professional stance enables social workers to determine whether a particular African clan will be best served along the lines of Afrocentric social work or Eurocentric social work. To successfully transform social work services from the Western dominated mainstream social work to Afrocentric social work requires that senior social workers, supervisors, service point managers and heads of social work departments in health care facilities consider reviewing and re-organizing the following services or aspects of services:

- Social work managers need to promote and streamline personalized intervention plans that indicate clearly which worldview will underpin the intervention, meaning that a one size-fits-all approach has to be avoided, requiring intense assessment to determine the actual needs of each African clan requesting social work assistance.
- Managers need to promote the framework for cultural relativity with an option for Afrocentric social work for Africans and any client requiring it.
- Managers need to re-organise work processes and the physical environment as well as resource allocation to cater for Afrocentric social work services and eliminate the Eurocentric bias embodied in the content and form of professional work including the physical space where professional helping takes place.
- The managers need to promote clan-centred instead of family-centred or client centred social work services when assisting African clans raising children with DS. They also need to ensure that adequate resources are allocated for clan visits and alternative professional interaction with the clans.

- The managers need to promote usage of different languages and cultural competency and awareness. Social workers have to be motivated to learn other languages and ensure that they are also able to communicate in the language of the community they are serving. This will facilitate the helping relationship that is characterized by trust as the clientele will see that the social worker is genuinely interested in them as people within their cultural context.
  
- The managers need to encourage the rest of the multi-disciplinary team to embrace Afrocentric approach to care, particularly clan-centred services to African clans raising children with DS.
  
- The managers need to ensure regular engagement of social work staff on the Afrocentric social work guidelines and encourage giving and receiving of regular feedback about Afrocentric social work services to African clans raising children with DS.
  
- Managers need to consider scheduling of medical and allied health professionals during sessions with the African clan to allow them an opportunity to interact with the clan in a one-stop service arrangement.
  
- A review of referral procedures and intervention processes to make them more Afrocentric and amenable to the needs and interests of the African clan system raising children with DS is of paramount importance. For example, allow for prolonged interventions that are affectionate and mutually beneficial to the client and social worker when working with African clans raising children with DS.
  
- Managers need to also consider instituting appropriate systems to monitor staff during work hours so that they can take responsibility whether at the service point/health facility or out during home visits to make sure that they are doing their work properly when servicing African clans raising children with DS. The personal and flexible nature of Afrocentric social work may open itself up for abuse by unscrupulous practitioners and therefore stringent control measures need to be put in place to monitor the situation.

- Afrocentric social work services within the health care settings require the formalization of regular multi-disciplinary meetings to review client care services. This will also provide an opportunity for the team to share important experiences and lessons that could be utilized for total quality improvement which caters for both clients and service providers.
- Lastly, managers need to develop and deploy total quality improvement approaches for Afrocentric social work services with African clans raising children with DS. This may include systems for receiving and analyzing suggestions for re-organization of services.

➤ **Integration and coordination of services**

As shown by the research findings, the African families raising children with DS go through different service providers as part of the treatment, care and management of the DS condition. These include medical and allied-medical professional interventions within the health care settings and outside. To enhance the experience of the African families, services need to be delivered in a coordinated manner among the different service providers.

The following guidelines are provided to help offer a more integrated and coordinated service:

- All African mothers identified as high-risk for giving birth to a child with DS in health care facilities should have individualized/personalized care plans that reflect activities or actions aimed at achieving their identified goals. It is important that this is done as early as pre-diagnosis of DS so that the mother and the African clan are also made aware of the risks and receive necessary psychosocial preparation. Social workers in health care settings may put efforts to ensure that they are able to identify and support these African mothers during the course of their prenatal care as most of the anxiety is raised at this stage particularly for those identified as high-risk of giving birth to a child with DS.

- Promote teamwork and an Afrocentric spirit amongst members of the multi-disciplinary team within the health care setting. This could help with effective communication and reduce fragmentation while ensuring that all service providers involved in the care of the African mother obtain the requisite information to guide her care.
- Regularly solicit the African mother's perceptions about the coordination of care or services and make this information available to relevant care providers involved in the care process. The social worker through case management may take the opportunity and assume responsibility to establish effective systems for giving and receiving feedback between members of the multi-disciplinary team and the African mother under their care.
- As practicable as possible, social workers may put measures in place for mothers at risk or with a child with clinical features or a child with a confirmed diagnosis of DS to be able to source all needed services, including laboratory, diagnostic and pharmaceutical services from one point within the health care facility. This will require joint planning and continuous collaboration between members of the multi-disciplinary team and the social worker is well placed to facilitate this process so that at the end, the discussions during sessions look at all these issues holistically.

➤ **Staff health and wellness**

Promoting Afrocentric social work services is not only limited to issues seeking to enhance the experience of the external client (African families raising children with DS). From a management point of view, the experiences as well as the health and wellness of the internal client (social worker as internal clients of management, particularly human resource management) are equally important and should be given adequate attention. Thus, considerable attention must also be given to the experience of social workers. This is in line with the cosmic view of phenomena. The Afrocentric philosophy advances that everything is connected and related in some ways. As outlined by Frampton et al. (2008:195), providing client-centred care requires that the staff give tremendous amounts of themselves (both physically and emotionally) and acknowledging and being responsive to their experience, and the multi-faceted

demands placed on them every day, is fundamental to the achievement of effective Afrocentric and clan-centred social work services. The dual focus on the experience of the helper and the helped is consistent with the Afrocentric worldview. In Afrocentric social work, the emphasis is on mutuality and affective professional relationships where the helper and the helped give and receive feedback and lessons during the course of the intervention. In the same spirit, Afrocentric social work services should put in place effective measures and systems to promote the health and wellness of social work staff. These can be achieved through adhering to the following guidelines:

- Service point managers, heads of social work departments and units as well as supervisors may endeavor to determine and address the needs of the social work staff rendering Afrocentric social work to African clans raising children with DS such as providing adequate operational resources, on-going staff and personal development as well as incentivizing superior performance.
- The management team or leadership needs to ensure the availability and utilization of employee health and wellness programmes, particularly the employee assistance programmes (EAP) which offer psychosocial support to employees and demonstrate care for employees by the employers. It is important that the services are indigenized to reflect the Afrocentric paradigm.
- It is imperative to institute performance management and recognition programmes that benefit all social workers whose practice is consistent with the Afrocentric paradigm. Clear performance standards and indicators consistent with the African worldview should be developed and used to identify and reward peak performance accordingly. Performance rewards should also be consistent with the African worldview and not be limited to material rewards, but embrace other forms of recognition prevalent in the African paradigm such as awarding social workers with symbolic honorary awards in line with cultural heritage. Social workers may be awarded with a spear or a torch symbolizing the impact of their work in addition to any other available rewards such as monetary rewards.

- Amongst other forms of recognition and reward systems include praises and self-recitations as prevalent amongst African ethnic groups based on personal achievements. This should also include spiritual fulfillment and joy found in helping.

➤ **On-going monitoring and evaluation**

The implementation of Afrocentric social work services with African clans raising children with DS in health care settings and outside in the community is a systematic process that requires on-going monitoring as well as baseline and interval evaluation of the impact and changes experienced by the clients and social workers. This is important for the continuous improvement of services and optimization of quality and responsiveness. Thus, it is essential that once Afrocentric social work services are implemented, an integral system of continuous monitoring and evaluation should be developed and deployed to monitor the impact of specific interventions and change strategies, where warranted. Equally important is the ability of the Afrocentric social work fraternity to tap into the feedback generated through these built-in monitoring and evaluation systems and processes to improve services and the overall client's experience. Therefore, these built-in measurements and feedback systems should be designed and streamlined to directly feed into specific intervention and process improvements.

Therefore, it is proposed that:

- Systems for regular monitoring and feedback on Afrocentric social work services with African clans raising children with DS need to be put in place in all social work departments in health care settings as well as community service points (DSD).
- Where possible, regular surveys need to be conducted at least twice a year focusing on both staff and African clan's satisfaction in all social work departments in health care settings and community service points (DSD) offering Afrocentric social work services to African clans raising children with DS.
- The social workers involved in rendering services to African clans raising children with DS may also look into tracking data on inputs, processes and outcome of

their services. Such information may then be used for benchmarking and improvement of service quality.

- At the individual intervention level, the social worker facilitating the intervention needs to engage clients in an objective evaluation of the helping process and outcomes. Social workers need to find out from the African clans receiving the services, what they thought about their care, progress and achievement of their goals. This may be done on a continuous basis and for every session with the African clan raising a child with DS.

#### **6.4 Summary of the chapter**

This chapter covered the Afrocentric social work practice guidelines developed by the researcher. The guidelines were developed on the basis of the findings of the study conducted with African clans raising children with DS and the interviews conducted with social workers assisting them. The discussion of the guidelines started with a brief introductory discussion followed by the purpose, scope, elements as well as a discussion of the process followed when the guidelines were developed. This was then followed by a detailed discussion of the guidelines divided into two categories: those relating to direct social work practice with clients and the second category that related to organizational conditions necessary for successful implementation of the guidelines. Given that the entire social work knowledge base as well as the practice environment has been developed and modelled on the Eurocentric worldview, it was necessary that the chapter not only offer technical guidelines on how to implement Afrocentric social work with African families raising children with DS, but concomitantly provide additional guidelines on ways to address organizational factors necessary for effective implementation of Afrocentric social work services. This is on the basis that the technical guidelines may not materialize on their own within the current organizational climate characterized by colonial styled physical spaces that are not accommodative and at times perceived to be or in actual fact antagonistic towards the African heritage. Therefore, there is a need for re-arrangements, transformation and alterations of both the content and form/outlook of social work in the African context.

Although the guidelines were developed for Afrocentric social work services with African clans raising children with DS, they can be adapted and used for generic social work services with Africans in different settings and fields of social work service. Afrocentric social work services provide an essential alternative to the Eurocentric mainstream social work and a vital means through which various psychosocial challenges confronting African individuals and clans can be understood and addressed. Afrocentric social work services present an alternative to the dominance of the Eurocentric worldview over the knowledge base of mainstream social work. Most importantly, the proliferation of Afrocentric social work presents an opportunity for the restoration of the African cultural heritage and traditions that were destroyed by the advent of Eurocentrism and colonialism.

## **CHAPTER SEVEN**

### **SUMMARY, CONCLUSIONS AND RECOMMENDATIONS OF THE STUDY**

#### **7.1 Introduction**

The purpose of this study was to develop an in-depth understanding of the issues related to the identity, experiences, and coping mechanisms of African families raising children with Down syndrome (DS) as well as the exploration of the opinions of social workers assisting them regarding congruence between social work services and the cultural orientation of African families. An in-depth understanding of the above issues was used as the basis for development of indigenised social work practice guidelines for social workers assisting African families raising children with DS. The guidelines that were developed based on the findings of this study are expected to contribute to the improvement of social work services in this particular field by making them become African clan-centred. The study engaged both the African families raising children with DS as well as social workers assisting them with the aim of obtaining a comprehensive view and understanding of their experiences in this regard.

#### **7.2 Summary of the thesis**

This section provides a summary of the whole research report, presented chapter by chapter.

##### **➤ Summary of Chapter 1: Introduction and general orientation of the study**

The first section of the chapter provided a general overview and background of the study. In this section the medical condition (DS) was explained alongside its implications for affected families. The chapter also described in detail the historical background of the medical condition, its characteristics, incidences and prevalence worldwide as well as in South Africa. The chapter also covered the problem statement, the aim, research questions and objectives of the study. Furthermore, the philosophical grounding and the theoretical framework was also discussed in this chapter. The thesis was developed from an African existential philosophical lens using

three theoretical perspectives. The theoretical perspectives used in this study are: social constructionism and constructivism, the eco-systems theory and the strengths perspective.

Ethical considerations also formed part of the chapter guiding the researcher to act within ethical confines so as to prevent harm and to protect the integrity of participants. The chapter was concluded with a clarification of the concepts used in the study, an outline of the thesis as well as the limitations of the study.

### ➤ **Summary of Chapter 2: Application of the research methodology**

A detailed account of the research methodology used in the study as well as how it was applied is provided in chapter 2. The study utilised a qualitative research approach. In line with the research questions, aims and objectives outlined earlier, the study adopted a phenomenological, exploratory, descriptive and contextual research. The discussion on the research methods covered population, sampling, pilot-testing of the data collection tools, data collection, data analysis and data verification. The study was conducted in Gauteng, Limpopo, Mpumalanga and the North-West Province. The research population consisted of two categories. Firstly, it included African families raising children with DS older than a year, residing in both the rural and urban areas of the four provinces mentioned above. The interviews in the first category took two forms, namely, semi-structured interviews with the African families raising children with DS, and focus group interviews made up of the primary caregivers of the child with DS (biological mothers or father and/or family guardians). The second category of the sample included social workers providing professional services to the African families, either from the various hospitals or DSD in their respective areas of residence, in the four mentioned provinces. The sampling method used was purposive owing to the fact that the researcher was looking for specific attributes in participants. Additionally, the snowball or network sampling technique was used to get the identified participants to assist in locating others.

Data were collected through interviews using three separate data collection tools. There were two different data collection tools used for the first category of the sample, namely, interviews involving members of the African families raising children with DS.

One of them being a list of focus group prompts used for the focus group and another one being an interview guide for the African family. The second category of interviews was conducted with the social workers and a separate interview guide was developed and used for the social workers. All the interviews were digitally recorded and transcribed. For purposes of pilot-testing data collection tools, a small sample with a total headcount of ten (10) participants from the same research population of the study was selected. The researcher did not make any changes to the data collection tools after pilot-testing as the results from the pilot-test were consistent with the researcher's expectations. The qualitative data were analysed following the traditional methods of qualitative data analysis adapted from Terre Blanche et al. (2006:33). In order to establish the level of confidence in relation to the extent to which the collected data represented the genuine meanings of participants, Guba's model (in Krefting, 1991:214) of ensuring the trustworthiness of qualitative data was used for data verification in this study.

➤ **Summary of Chapter 3: The historical overview of social work**

This chapter examined the origins and development of social work internationally and in South Africa, culminating into a review of contemporary social work theory and practice. The discussion showed that the knowledge and theoretical base of social work at all levels remains skewed and biased towards the global north and west. Similarly, local South African social work mirrors the international version in content and form. Thus, a need for indigenization was demonstrated. The literature also pointed to the emergence of an international social work domain coupled with its concomitant drive towards universalisation of social work knowledge. The knowledge and theoretical base of social work remains Eurocentric and no attempts were made at an international level to legitimize and mainstream indigenous social work typologies as may exist world-wide.

➤ **Summary of Chapter 4: The nature of the African family, DS, stress and grieving as well as contemporary social work practice in South Africa.**

The traditional African family system is presented in this chapter. In analyzing available content, it was found that the narrative used within the conventional discourse of the

family as a social system presumed a shared understanding which was found to be misleading and mired in conceptual confusion, given the stark contrast between the African and European worldview. The discussion illuminated the biased and skewed analysis of the traditional clan system using western conceived theoretical lenses that lacked resonance with the reality of traditional African life. It was noted that the traditional clan system instead of family was organically evolving, whilst also being forced to adapt (involuntarily) to the socio-economic circumstances imposed on it by the colonial, apartheid and postcolonial global capitalistic systems for survival.

The discussion on the traditional African family was followed by a discussion on the DS condition and related medical genetic services. The management, treatment, care and support for children with DS in relation to available services was discussed. The services include amongst others; medical genetic services, genetic counselling services as well as a range of other related therapeutic services. This was followed by a discussion on the stress phenomenon as a major challenge for individuals and families affected by the DS condition. The section provided a general discussion of stress as a psychosocial phenomenon, its varied reactions and various coping strategies. The discussion on the grieving process was guided by Kübler-Ross' (1969) 'Death and Dying' process. The latter was used to illuminate grieving generally. The grieving process was used to understand how African families raising children with DS might have dealt with the process of coming to terms with the loss of a dream for a normal child. The discussion on the contemporary South African social work practice and health behaviors of Africans mapped out the landscape of contemporary social work practice in South Africa. The discussion also explored some of the typical health behaviors of Africans. It juxtaposed contemporary social work practice in South Africa against typical African practices and behaviors so as to highlight areas of possible disjuncture, gaps and synergies that the study attempted to address.

➤ **Summary of Chapter 5: Presentation and analysis of research data.**

The qualitative data collected through semi-structured interviews from African families raising children with DS and social workers as well as the analysis thereof are presented in chapter 5. Themes and sub-themes that emerged in relation to the nature and experiences of the African family raising a child with DS, the social workers

assisting them, as well as suggestions from both for the improvement of social work services so that they become culturally appropriate, were discussed. The themes and sub-themes are summarized as follows:

### **Theme 1: The nature of the African clan raising children with DS**

The nature of the African clan raising children with DS as a major theme consisted of two sub-themes that were explored. The sub-themes are as follows:

#### **Sub-theme 1.1: The clan identity and structure.**

None of the ethnicities interviewed had a notion of family as a concept as described from the western perspective, in their cultural vocabulary. The concept family was alien. The data revealed the existence of relationships organised through a clan system. Each clan retains a unique identity and a totem. The clan identity and use of totems that mainly followed a patrilineal kinship (clan identity explained and followed through a paternal line). However, there was evidence of the existence of both patrilineal and matrilineal kinship systems. Although some families did not mention the relationship between the paternal and maternal side of the kinship as forming part of their kinship system during the course of the interview, their biographical details attested to it. They had in one household family members who are related and linked to the family through the paternal line and others linked to the family through a maternal lineage. All these people were regarded as family. This, therefore, confirms the existence of matrilineal kinship in the traditional African clan system. Essentially the above finding on the co-existence of patrilineal and matrilineal kinship reaffirms the collectivist and integrated cosmos within the African worldview and philosophy where everything is connected and interlinked.

The data showed that the African clan system has a unique structure comprising of a much wider circle of people related by blood and marriage. Thus there is no particular configuration of the structure of the clan as it is blended. It covers a series of households either cohabiting or leaving separately, whose relationships are based on custom and blood. This configuration of kinship relations is referred to as a clan in the traditional African context. These wider circles of people referred to as 'extended

family' in the conventional sense of the family are not only viewed as a clan but in some instances are found to share a household.

### **Sub-theme 1.2: Clan functioning, culture and tradition**

The data pointed to a unique way of functioning of the African clans raising children with DS which was common across the different ethnic groups, but in sharp contrast to the functioning of the conventional family system. The data showed that different members of the clan have different roles. Grandfathers and grandmothers play a unique role, and aunts also have a special role in the clan system. Grandparents serve as advisors and are seen as think tanks for the household raising a child with DS. Younger couples and clan members usually turn to them for advice and material support in times of difficulty. Grandfathers are also perceived as anchors for the male members of the clan, while grandmothers anchor the females and serve as midwives when children are born at home as reflected by most clan members whose child with DS was born at home, particularly those based in rural areas. Grandparents are custodians of wisdom and information about the identity, history and functioning of the clan and life in general. They are also problem solvers and a valued social support system for the younger members of the clan. They will always be the ones to be consulted when there are problems in the clan and their intervention is expected to be widely accepted and respected by everyone in the clan. Any defiance is viewed as deviant and punishable by ancestors. Uncles and aunts also play a significant role in marriage negotiations and representing the matrilineal side of the kinship when it comes to the bride and her children.

The issue of elders performing certain rituals following the birth of a child with DS seems to be a standard cultural practice across different African ethnicities although it is applied differently depending on the clan's belief system. This practice is generally followed when children are born regardless of the condition of the child. Some participants who are inclined to Christianity reported that they deal with it through a prayer service, while those who believe in traditional practices pointed to traditional rituals and ceremonies as discussed above. Some amongst those that belong to the so called charismatic churches were critical and dismissed all speculations that if the rituals are not performed the child may experience some problems as biblically

unfounded and flawed. They instead presented faith as the ultimate determinant of one's fate rather than rituals and traditional practices.

African culture appears to be homogenous, but heterogeneous in its practice, meaning that the African culture is essentially homogenous at a cultural level. It is observed that in effect the same culture is practiced differently in different contexts. This accounts for some of the deviations observed. For instance, the practice of '*lobola*' (bride price) is a cultural construct homogeneous across all African cultures, but how it is practiced will vary from one context to another.

## **Theme 2: The lived experiences of the African clan with regard to raising a child with DS.**

The above theme known as 'lived experiences of the African clan' comprises of two sub-themes; that is a sub-theme on how the families received the bad news about the child's diagnosis of DS and a sub-theme on their coping mechanisms thereafter. This theme captures the reflections on the experiences as lived and accounted by the African clans themselves.

### **Sub-theme 2.1: How the clan received the bad news that their child has DS.**

Those residing in deep rural areas inhabited largely by Africans and characterised by lack of health facilities were found to have more incidences of child births at home under the guidance of elders as midwives whilst those found in more affluent urban areas, historically inhabited largely by whites with ample health facilities delivered their children in hospitals. In line with the above, most of the DS diagnosis made in rural areas were based on the outcomes of a clinical examination, instead of diagnostic test results as seen with most children diagnosed in urban areas. All clinical diagnoses in rural areas were made long after birth and they were mainly clinical diagnosis (based on characteristic (clinical) features of the child as identified on examination by a medical doctor) without confirmatory diagnostic tests while their urban counterparts had their children diagnosed immediately after birth or within a short period after birth. Worse, the parents of the children with DS residing in rural areas had no access to genetic counselling or even a specialist medical geneticist. They were mainly assisted

by general practitioners and some referred to specialists such as gynaecologists and obstetricians with a few of them seeing a paediatrician at their respective district hospitals. Some of the rural-based African clans raising children with DS never received a diagnosis, but realised after delayed milestones that there was something wrong with their child and started investigating until they established through interactions with the DSA that the child had DS.

On the basis of the uneven spread of resources across rural and urban areas, the data reveals that the availability of DS related and necessary support services depends on geographic location with urban areas at a better position than rural areas. All functional and well-resourced support groups are in urban areas. None of the existing support groups in rural areas are coordinated or facilitated by qualified social workers. Instead they are coordinated by lay-volunteers.

Some of the African clans based in Gauteng received genetic counselling following a positive diagnosis of DS on their child. A considerable number of African clans of children with DS in urban areas received pre-natal screening and diagnostic tests, particularly those identified as high risk associated with advanced maternal age (AMA). None of the biological mothers or guardians interviewed in this study received assistance from a social worker at the hospital. Therefore no social work counselling or psychosocial support through individual or group intervention was provided within a hospital setting. This is despite the fact that almost all hospitals, especially in Gauteng, have social workers.

There is no established protocol and guidelines outlining the process of disclosing the diagnosis of DS in hospitals except for the genetic counselling clinics found in fewer hospitals. The parents and/or guardians of the children with DS reported that due to the fact that the bad news are delivered to them, they then have a responsibility to take the news to the clan which in itself becomes a traumatic process. This is because often they themselves have little understanding of the condition and it is further complicated by the lack of African names and descriptions for DS and its features. Additionally, there are a number of society-related stereotypes and stigma around congenital disability and mental retardation that clans have to deal with. The stigma and stereotypes may either come from within the clans or outside. The participants in the

focus group discussions expressed their desire for the disclosure of bad news to be done in a clan meeting with the significant others. Some of the biological mothers reported negative reactions from significant others in the clans including outright rejection of the child with DS as not belonging to the clan.

The above findings on how the African clan received the bad news about the diagnosis of a child with DS confirmed the paradoxical relationship between the African and Eurocentric worldview. The hospital as an institution within the broader health-care system is underpinned by the Eurocentric worldview, while the African clan raising children with DS subscribe to the African worldview. The hospital delivers the news to the mother or a couple accompanied by counselling, but the entire clan system is left out. The couple or the mother is left with the burden of having to communicate the bad news to the clan. This is often problematic and unbearable for the mother or the couple given that she/they will still be grieving.

### **Sub-theme 2.2: Coping mechanisms with regard to raising a child with DS**

The data shows that numerous marriages and relationships broke down as a result of the birth of a child with DS. Some African clans attributed the birth of a child with DS to witchcraft and evil spirits such as '*kgaba*', while others accepted the scientific explanation given by the medical experts. The understanding of the clan about the cause of DS influenced how they managed the condition. In some instances, divisions in the clans were witnessed regarding the cause of the condition and the intervention needed. Some clan members who were inclined to traditional practices preferred the challenge to be addressed through traditional spiritual measures while others who subscribed to the Christian faith preferred dealing with it using various spiritual approaches. The data showed that different clans experiencing the same stressful demands imposed by their raising of a child with DS at different times responded to the demands differently. Their different ways of responding to the pressures brought about by the challenge of raising a child with DS may be attributed to their different capacities from time to time. The data highlighted an important aspect in the manner in which African clans dealt with the occurrence of disruptive incidences in their lives. On the basis of the data presented, it appears that African clans tended to focus on three aspects when dealing with the challenge of raising a child with DS. The three aspects

are causality, purpose and function. Causality relates to information about the aetiology or cause of the condition. The participants valued the information received about the condition as being of great value in helping them understand and manage the condition. Secondly, purpose relates to God's intentions when giving them a child with DS. Similar to causality, the purpose is believed to cast the clan's burdens on God's shoulders. Thirdly, function relates to what the incidence of the birth of a child with DS does to the clan. They believed that the birth of a child with DS changed their lives significantly. Some were brought closer to God and ancestors. For others, it opened doors for good things in their lives such as employment and success in other areas of life.

In all challenges and difficulties encountered none of the clans and their members who participated in the focus group saw a need to consult a social worker. They resorted to established social support systems found within the clan system. Most of the participants reported that other family members called for '*lesiko or isiko*' meaning a traditional ceremony to petition the ancestors to intervene and help the child, while others who were more inclined to Christianity tended to rely on the Holy Scriptures for guidance.

The findings confirmed earlier contributions by African scholars (Ani, 1994:43; Schiele, 1997:803; Osei-Hwedie, 2002:312; Biko, 1978/2004:29; Sherr, 2006:5; Asante, 2006:648; Fanon, 1952/2008:166; More, 2008:47; Schiele, 2013; Sithole, 2016a) that together asserted the existence of a unique worldview in Africa. In line with social constructionism, the African families raising children with DS as does the entire African population collectively developed a unique way of making meaning, communicating and passing knowledge which is unique to the African context. This forms part of the unique subjective and lived experience of Africans. This has proven to be difficult for anyone outside the subjective existential condition of African subjectivity to understand or embrace leading to an assertion within African circles that only Africans themselves may effectively articulate their lived experience. The findings of this study as well as others conducted before by non-African researchers has demonstrated unequivocally the tragedy of misinterpretations and misrepresentations caused by an attempt by an outsider to remotely read the experiences of Africans using foreign lenses (western worldview and cultural thought).

The issue of spirituality and affection as sources of knowledge in addition to objective truth is central to the African worldview contrary to the western worldview and cultural thought that relies exclusively on objective reality and knowledge. Given that Africans do not rely solely on objective knowledge, but also on spiritual and affective sources of knowledge and wisdom, social workers may also have to consider that in African cultures, knowledge and wisdom is a function of age. Therefore, older clients may struggle to accept the counsel of younger social workers.

The African worldview is holistic contrary to the fragmentation found in Western knowledge systems created by disciplinary decadency. As a result, specific detail does not matter in the manner in which Africans manage social challenges. All conditions involving some forms of disability are viewed as one form with no regard to their heterogeneity and different classifications.

### **Theme 3: The African clan's intersection with social work while raising the child with DS and their suggestion for improvement of social work services.**

The following section focuses on the summary of the reflections by the African clan raising children with DS regarding their experiences with social workers. The first part deals with the account of African clans regarding social work services in hospital and out in the community, while the second one deals with their experiences with social workers while raising children with DS and the third one deals with their suggestions regarding improvement of social work services to ensure that they are assisted in a culturally sensitive manner.

#### **Sub-theme 3.1: Social work services in the hospital and community**

The data gathered shows that, although most public hospitals have social workers in their staff compliments, patients still go without receiving any assistance from social work services. All participants interviewed reported that they never received support from a social worker within the healthcare setting. The same situation seems to be the case in the communities where the DSD is the custodian. Most of the participants interviewed reported that they did not receive any social work assistance in the

community. Few participants who were assisted by social workers in the community seem to have been those clans whose children were removed from school due to their stage of mental retardation and need for placement at a special school as well as those whose children were victims of sexual offences (raped, for instance) in the community and the intervention of social workers was in response to the rape incidence rather than the DS condition. As a result there is little data from African clans relating to the nature of social work services received by the clans from social workers. The area remains neglected by the social work profession in South Africa despite the huge impact it has on the psychosocial front as well as the household finances due to its disabling nature.

The few that received social work intervention reported that the social worker concerned chose to either work with the mother or the child and the two were targeted depending on the nature of their presenting challenge. For instance, if the mother presented with a lack of proper accommodation for the child, the social worker would work towards addressing such a problem. If the social worker assessed and resolved that the child needed institutionalization, he or she would work towards getting the child into an appropriate institution without taking the African clan into his/her confidence. Again, the lack of a holistic view of the client's situation as revealed by the findings seems to have been an act of omission on the part of the social workers as this is taught to them during training.

### **Sub-theme 3.2: How the family experienced social work services in the hospital and the community**

On the basis of the fact that the African families interviewed in this study did not receive social work services directly related to helping them cope with raising a child with DS as such, both in hospital and in the community, this theme pertaining to the experiences of social work service by African families remains not adequately answered. Therefore, it can be deduced that there is lack of structured social work services for African families raising children with DS in the hospitals and the community.

**Sub-theme 3.3: The African families' suggestions regarding how they would like to be assisted by social workers in a culturally congruent manner when raising their children with DS.**

Although almost all of the African families interviewed had not received any help from social workers, they were able to reflect on their expectations for social work services. They could not spell out the significance of social work support for their particular situation while raising children with DS. Therefore, they could not even ask for such services, but when offered they would not turn them down. However, they acknowledged that in some instances they are compelled to see social workers, particularly when they need to apply for social security or when they need a special school for their children. For those who came into contact with the social worker due to an unfortunate situation like rape of the child with DS expressed dissatisfaction with the manner in which the social workers handled their cases given that no convictions were made on all the cases despite the interventions of social workers.

However, despite the above background, the African clans were still able to reflect on how they would like to be assisted by social workers in a culturally congruent manner. They would like social workers to assist them to deal with stressful reactions to the experience of raising children with DS. The African clans did not use the word counselling, but instead used the word emotional support and advice. Various vernacular words were employed such as 'thekgo ya semoya', 'nseketelo wa ximoya', 'ukududuzwa' which all implies emotional support. They also used the word 'advice' in their narrative. They expected social workers to provide advice on how to manage emotions and the DS condition within the clan system and the community. The data shows that they prefer a more clan-focused social work intervention. The clans also added that they struggled with accessing grants for their children. They would like social workers to play a more active role in this regard to ensure that the children from poverty-stricken families and deserving are assisted quickly to access the grants. The African clans also added that they must be helped as support groups to develop personal and organizational capacity to formalize their work through building sustainable organizations, well-resourced to tackle all challenges related to raising children with DS at their local community level. African clans would like social workers to help them secure land and funding for their organizations to operate from, as well as

ensure that they guide the process. They also expressed their desire for the social workers to ensure that special schools are built locally so that their children can attend daily from home and not have to be sent far away to a boarding school. The participants from African clans expressed their distaste of distant boarding schools because of their mistrust for such schools. They reported that it is emotionally difficult for them to have to accept that their children with disabilities are taken away to a far place where there are always possibilities of them being ill-treated. They would rather prefer that they be given an opportunity to raise their own children as they know their needs better.

**Theme 4: The social workers' opinions regarding the level of congruence between the social work services rendered to African families raising children with DS and the needs of these families, as well as their suggestions for the improvement of social work services.**

This section deals with the summary of the opinions of social workers regarding the level of congruence between the social work services rendered to African families raising children with DS and the needs of these families. Three sub-themes emerged from the data, namely, one relating to their experiences of working with African families, how they manage the lack of fit between social work and the African worldview, as well as their suggestions for the improvement of social work services.

**Sub-theme 4.1: Social worker's experiences of working with African families with regard to services and reception of such services.**

The data from the health-care setting revealed that there is no established protocol or guidelines for their work with African families raising children with DS within the hospital environment. Their professional interventions focused mainly on counselling with individuals and/or groups of patients admitted to the hospital and sometimes where necessary and compelling, they would involve a significant other in the counselling process. The data shows that social workers in health-care settings generally work with individuals (patients). Furthermore, there was no indication of work with the clan in all data relating to social work in health-care. Some social workers in health-care settings believed that there is lack of fit between social work and African

culture, whilst others believed that social work is applicable and adjustable to all cultures. The social workers in health-care settings reported that they mainly provided short-term counselling such as trauma counselling and crisis intervention and never collaborated with DSD social workers unless, the client in the hospital did not have a family and, as part of discharge planning, they were compelled to find alternative placement for the client or when dealing with unwanted children that needed adoption. The data shows that social workers in health-care settings function within a multi-disciplinary team, but they perceive their role within the team as weakened by the fact that they are looked down upon and occupy an inferior position. The social workers in health-care settings confirmed that they do not focus on spirituality and affect, but rather on the objective issues presented. They further reflected on their discomfort with the cosmic view of life as presented by African families. Most social workers in health-care reported that they would not be willing to engage on any issues beyond the objective aspects of health and what is objectively viewed as being in the best interest of the patient as their client. They reported that they would, however, be open to hear and listen to variant views, but would not allow such to define the focus of their intervention.

Similarly, there is no protocol for social work services rendered in the community by social workers from the DSD, despite the existence of stringent protocols for social security services. The social workers in the community face similar challenges of lack of resources as those in health-care settings. The lack of professional standing and autonomy was also a big issue for them. Unlike those in health-care settings that had some level of professional standing, however limited, the social workers from the DSD did not have a sense of professional standing and autonomy. This they explain as their inability to conduct their business in a manner that is consistent with the professional norms and standards as embodied in the body of knowledge, values and principles of social work. The data shared shows that the social workers were not given a safe space to practice social work as taught during their training. Instead, they were forced to perform menial tasks that did not require any professional skill or competency. The social workers further highlighted that they were not given adequate resources to enable them to do their business in a manner that observes and upholds the values and principles of social work. For instance, they did not have adequate and convenient office space for privacy in line with the ethical value of confidentiality. As a result, they

could not effectively work with clients in a manner that upholds the value of confidentiality.

Furthermore, they reported that in the course of their work in the government sector, they are often subjected to political interference. Political interference involves dealing with political instructions from their principals to perform certain tasks that they view as being outside the scope of their professional practice. However, due to their weak position in the organisational strata, they are compelled to do whatever their principals order them to do due to fear of victimisation given the lack of professional protection. Some reported that at times they are called in to facilitate politically motivated initiatives that are clearly outside the scope of practice of social work.

#### **Sub-theme 4.2: How social workers manage the lack of fit between social work practice and the contextual realities of the African families**

Some social workers practising within health-care settings were adamant that their interventions did not in any way conflict with African culture. They felt that they are able to adapt their interventions accordingly whenever they deal with Africans to ensure that there is no tension. Some of them disagreed, indicating that social work methods and techniques are alien to the African way of doing things. They highlighted the fact that often such a tension is modified by the fact that the social workers are Africans themselves and tend to act in a manner that is consistent with African culture, something which a non-African would find difficult to do.

The DSD social workers were mainly in agreement that social work with African people cannot be the same with social work practice with white people as the two groups have different cultural orientations and world view. They believed that they are in a much better position to connect better with fellow Africans and did not believe that a white social worker would be in a position to connect with African people because of the cultural differences. However, their biggest frustration was that they were not even given an opportunity to practice social work. They are subjected to political interference. For instance, politicians would instruct their managers, most of whom are not social workers by profession to order social workers to distribute food parcels in the build-up towards major political events. Social workers would not have a say, but to

comply with the instruction from their principals. Refusal of such on the grounds that it falls outside the scope of practice of social work would amount to insubordination.

### **Sub-theme 4.3: Social workers' suggestions for improvement of social work services rendered to African families raising children with DS**

The social workers practicing within health-care settings suggested that there is an urgent need to beef up available human resources to allow them adequate time and space to perform their professional work properly in line with the set norms and standards. They also expressed concern that the limited human and material resources make it difficult for them to infuse a developmental paradigm/approach to their work. They complained that there is a critical shortage of social work staff resulting in them only attending to prioritised cases and leaving out the majority of clients who need their services. Social workers recommended that the African worldview be added to the social work curriculum at universities.

#### **➤ Summary of Chapter 6: The indigenous social work practice guidelines for assisting African clans raising children with DS.**

The developed guidelines for indigenous social work practice aimed at assisting clans raising children with DS are presented in this chapter. The guidelines are designed to be used in addition to other policies and documents that are available in the South African social and health services. The chapter is structured in three main sections, namely:

Section one outlined the process of developing the guidelines, definition of terms, scope of application, purpose, objectives, guiding principles and attributes for the guidelines. The idea and process of developing these guidelines emanated from the concerns raised by several African scholars in literature about the lack of fit between social work methods and models developed in the Euro-North American context to African contextual issues and challenges. Additionally, professional reflections stemming from the researcher's practice experience as an African working with the African clientele in social work and the desire to make social work services more responsive and clan-centred. The main object was to provide empirically-based practice guidelines on Afrocentric or indigenous social work services to assist social

workers rendering African clan-centred services to African clans raising children with DS.

Section two dealt with the practice guidelines on Afrocentric social work services. This section provided the practice guidelines related to provision of Afrocentric social work services to African families raising children with DS.

### **7.3 Conclusions**

- The lived experiences of African families raising children with DS provided an essential lens and angle for understanding the interplay between the nature of the identity of the African family and the manner in which it deals with challenges associated with raising children with DS.
- This study demonstrated from a phenomenological viewpoint that African families raising children with DS constantly and silently wrestle their entanglement with a system of psychosocial support in the form of social work services rooted in naturalized and institutionalized Eurocentric paradigms which are in stark contrast with their own African worldview. As shown in literature and confirmed by this study, the theory, methods and models that determine the nature and purpose of social work interventions with African families are based on Eurocentric paradigms that lack resonance with African cultural essence. Consequently, social work interventions remain ineffective as a means to address psychosocial challenges facing African families raising children with DS.
- There is paradigmatic crisis in social work. The crisis stems from the paradoxical relationship between Eurocentrism underlying social work practice and the Afrocentric worldview and involves the silencing of the existential realities of Africans in the content and form of the social work helping process.
- While underscoring some areas of strength in the current system of mainstream social work, the thesis produced some valuable results that could be used to improve social work services and make them more responsive to the felt needs of the African family system raising children with DS whose indigenous knowledges were previously and continues to be ignored.

- As postulated in literature, the African families or clans are not exclusively for the man, his wife and their children as seen in western family types. Indeed, the traditional African family raising a child with DS participating in this study was found to be characterised by a unique form/nature and structure, different from the conventional conceptualisation of a family as it exists in the Eurocentric worldview. In fact, the concept family or even extended family does not exist within the traditional African social system. Instead, the African clan system was uncovered. Thus, on the basis of the unwavering evidence from the empirical study, the researcher found it prudent to use the concept 'African clan' in the place of 'African family' to remain consistent with the African social reality and lived experiences of Africans in the study. Thus, the researcher concludes that the clan system instead of a family system characterizes the African social context. Thus, an authentic analysis of social relations in this case should move from a premise of a clan system.
- The patrilineal and matrilineal kinship networks characterising the traditional African clan system function together like two sides of the same coin. Furthermore, these kinship networks are underpinned by an inclination towards spirituality and affection as both sources of knowledge, being and power over and above objective truth.
- Marriage through payment of '*lobola*' (bride price) remains an important signifier of a transition of a bride from her own paternal family identity and assumption of a new family identity of her husband's paternal lineage. It is worth emphasizing as did earlier literature that, despite the pressure and assault imposed by colonization, apartheid and modernity on the traditional African clan system, it remained resilient and retained its unique character distinct from the western nuclear family structure.
- Although most authors writing about the nature of the identity of the African family system touched on the issue of the clan system, previous work has not specifically addressed the meanings attached to the clan and its associated facets such as the totem and clan praises. Thus, this thesis made a contribution in closing the knowledge gap by taking the discourse on the African clan system further to uncover its symbolism and underlying meanings which are crucial when considering how the clans deal with psychosocial challenges. The thesis

reveals that the clan as an institution forms part of a central element of the African's identity, spirituality, cohesion and collective consciousness.

- The clan name system symbolises group support and cohesiveness given that whenever there is festivity, a ceremony, or a crisis in most African families, relatives and households belonging to the same clan pool their resources together both in cash and in kind towards such ceremony or crisis.
- The African clan system is not static, but continuously changing as does any other form of social structures as may exist world-wide.
- The African clan as a social system is made up of various interrelated and interdependent elements that work together to create the whole (African clan) wherein the elements function together towards equilibrium.
- The ecosystems theory assists in mapping the kinship networks found within the African clan system as constituting sub-systems of a whole African clan system. The data on the culture and tradition of the African clan have serious implications for how professionals such as social workers engage with African clans. Thus, it can be concluded that the social work profession cannot follow the same process used with conventional western families when dealing with Africans on the basis of the unique characteristics of the African clan system revealed in this study. The nature of social relations within the traditional African clan system calls for a focus on the system as a whole in order to harness the different roles players involved. Any intervention that does not tap into these important role players and their roles has a risk of imposing solutions that cannot be sustained or may instigate further tensions within the clan system.
- The employment of the theoretical framework including social constructivism, strengths perspective, and the ecosystems theory jointly with a critical historical analysis led to the mapping out of various historical and current macro level influences and forces of modernity and coloniality (socio-economic and political) that exerted influence on the traditional African clan system. This kind of analysis received less attention in social work over the years, despite the proverbial claim of the profession being anchored by the ecosystems theory.
- It is concluded that theories such as the strengths perspective and the ecosystems approach in their current modern or post- modern forms are limited as they do not offer social workers the possibility of facilitating real social change capable of shifting structural and systemic layers of oppression and

discrimination. The reason being that they do not challenge social workers to confront the naturalised, systemic, institutionalised and cyclical oppressive nature characterising the modern world based on dominant western worldviews. Instead of offering theoretical and methodological tools to defeat the multi-faceted Eurocentric hegemony, these frameworks serve as control measures advancing the conditions for the oppressive system to reproduce and recycle itself perpetually.

- Accordingly, the understanding flowing from a close examination of the unique identity of the African clan raising children with DS and their lived experiences led the researcher to a conclusion that concurs with earlier African scholars including Frantz Fanon and Steven Biko, who argued that the African existential condition can only be understood from the phenomenological/subjective view of Africans who live and experience it.
- When dealing with challenges associated with raising a child with DS, the African clan's concerns transcend pre-occupation with the etiology or cause of the condition as emphasised in the western paradigm. Although the etiology remains crucial, the African clan draws on its spirituality and affection to consider the purpose and function of such eventuality in the bigger scheme of things. The belief in the interconnectedness of things and events undergirded by spirituality makes it possible for the clan to function optimally with an understanding that everything happens for a reason and serves a particular purpose, hence, their ability to accept and move on with gratitude even in situations that might otherwise have been viewed negatively in a western worldview. This is crucial knowledge for the profession and academic discipline of social work as any form of psychosocial support in this regard would have to be tailored to engage all these issues if it were to be effective and sustainable.
- With regard to stress, it is concluded that stress reactions associated with DS may be effectively contained or worsened depending on how they are appraised. The appraisal is dependent on the individual or family/clan's capacity to deal with the demands of the stressful situation. Better capacity leads to better coping whereas lack of capacity may lead to more overwhelming degrees of stress reactions. Sometimes, negative appraisal may be attributed to lack of information.

- The traditional African clan seems to be alienated by the western-oriented social work currently practiced in South Africa. As a result the African clans do not consider social work services as a necessary form of psychosocial support when facing psychosocial challenges such as raising children with DS. The variety of theoretical conceptualizations and constructs found in the conventional knowledge base of social work all remain alien to the African way of life.
- The findings confirm arguments advanced in the literature that social workers in health care settings where social work is actively practiced have not critically engaged any of the theoretical constructs defining their roles to respond directly to the needs and aspirations of a unique African clientele. Thus, it is concluded that social workers continue to service the African clientele in the same way that they service everyone in the mainstream. The lack of focus on spirituality and affect is a case in point as well as their discomfort with the cosmic view of life as prevalent in African communities.
- Social work as a helping profession seemed to be unpopular amongst African clans raising children with DS. Despite the fact that almost all participants knew about social work, they did not perceive, recognize and consider it as an essential resource and support system. Thus, it appears that whether it was available or not, to them it did not matter. It seems that they would have not asked for it if they knew it was available anyway. The participants did not value the professional intervention as a necessary psychosocial healing process, but just as one of the practice formalities that needed to be complied with particularly as a means to access grants and other assistance for the welfare of the child. The researcher therefore concludes that social work is alien to the African families. They do not identify with the profession. This means that the profession needs to redefine itself in a manner that would create a different professional image that Africans can value, own and identify with as an essential support system.
- With regard to social workers, the empirical evidence points to the fact that not all practicing social workers are engaged in social work practice according to the training obtained at the institutions of higher education and prescribed in its professional scope of practice, norms and standards. The social workers employed by DSD for instance; are made to take instructions from non-social

work principals and politicians who understand very little about social work. Even more worrying is the fact that a bigger segment of the social work fraternity found within the DSD seem to be practicing something else other than social work, albeit in the name of social work. It appears that social workers in health care do practice social work although it remains clinical and focusing exclusively on individual clients. They rarely practice group work as a method of social work and seldom does community work. This is despite the proverbial call for a paradigm shift towards a developmental approach emphasizing a shift from micro to macro practice. Therefore, the researcher concludes that there is an urgent need for revitalization of the social work profession across different sectors. The SACSSP is better positioned to spearhead this process in collaboration with all stakeholders.

- Social workers seem to be aware of the developmental approach from their training. Meaning that institutions of higher education seem to have succeeded in infusing the developmental approach in their curriculum and the new crop of social workers has indeed internalized it although it is still not practiced.
- There is indeed lack of fit between social work services and the cultural orientation of African clients in this case the African clans raising children with DS emanating from a general disregard for the African worldview and cultural thought. The omission of the African worldview and cultural thought may be attributed to a number of factors including the fact that social workers may have failed to start where the client was and consequently missing out on important information. The social workers may also have failed to see things through the eyes of the client. The social workers may have ignored critical contextual issues that shaped the client's reality.
- There is a need for the development of a set of indigenized social work practice guidelines for social workers assisting families raising children with DS.
- Finally, all conclusions made in this thesis should be considered in the light of their limitations which include the fact that the research focused on African families raising children with DS and the guidelines developed specifically for social workers assisting this particular client system. This means that, although the findings and guidelines may be adapted or used beyond the specified client system, such use and adaptation should take into account the fact that the research focused on the particular client system.

## 7.4 Recommendations

The following recommendations have been formulated based on the whole research report.

- ❖ Recommendations in relation to the research methodology employed in this study

On the basis of the methodology employed in this study, it is recommended that future research make necessary methodological modifications to ensure consistency with the African research context. This would include, amongst other things, infusing spirituality and affect as additional sources of research data as well as mutuality in the relationship between the researcher and the researched. It also implies that the researcher works together with the research participants in the process of generating research data and creating meaning, meaning that the African research participants may need to be involved from beginning to end, not just as objects of information. Given that research interventions are meant to assist in identifying and solving problems, those affected by such problems ought to be accorded an opportunity to participate throughout the process with the guidance and support of the researcher. It should be equally acknowledged that the researcher may also be affected by the problem and therefore, s/he ought to also reflect on own experiences. This also implies that the researched jointly control and own the process and product of research and must be accorded such status as an ethical imperative.

- ❖ Recommendations in relation to indigenous social work services with African families raising children with DS

The following are recommendations related to indigenous social work services with African families raising children with DS. They include a focus on implementation of the practice guidelines, the role of professional and statutory bodies as well as the transformation imperative for social work practice, research and education.

- Recommendations on the implementation of the proposed indigenous social work guidelines for assisting African families raising children with DS

- It is recommended that further studies be conducted to assess the impact of the implementation of the practice guidelines for Afrocentric social work services and to develop them further, with a view to effectively respond to the felt needs of the African clientele.
- Lack of commitment to Afrocentrism on the part of social workers and management may stand in the way as barriers to the effective implementation and institutionalization of Afrocentric social work services. Therefore, all of the above issues need to be addressed and measures put in place to ensure that Afrocentric social work services are implemented and sustained. These include ensuring that a conducive organizational environment is created including having policies, regulations and protocols to guide implementation of Afrocentric social work services. On the flip side, re-organization of the physical space and infrastructure, adequate resources and logistics, adequate staff, balanced workload, proper training and induction may serve as positive reinforcement for effective implementation and sustainability of Afrocentric social work, hence the inclusion of organizational guidelines to the practice guidelines that came out of this study.
- In relation to the DS medical condition, its treatment, care and support, it is concluded that the government is already overburdened with pressing needs to respond to the devastating effects of the HIV and AIDS pandemic and, as a result, may find it difficult to allocate further resources to cater for a separate cadre of specialized genetic counsellors in health care. The absence of genetic counsellors/posts in the broader public health system, specifically at the primary health care level currently bears testimony to this observation. Where they are available, they practice privately, and various laboratories that provide testing for genetic conditions employ some. Therefore, social workers should be capacitated to step in and close the gap, particularly in poorly resourced areas. The creation of a limited specialized genetic counselling seems to have compounded this problem as it appears to be an unnecessary duplication of services that might have otherwise been rendered by social workers or psychologists in hospitals with training on medical genetics. This approach would strengthen primary health care service by taking services to the people, within the '*Bathopele*' (people first) Principles.

- Recommendations on other vital aspects of the profession including regulatory bodies and professional associations
- It is recommended that the SACSSP as a statutory body put measures in place to regulate the use of indigenous practice guidelines with African clans whose indigenous knowledge systems were previously and continues to be excluded from the body of knowledge underpinning mainstream social work as a social justice matter and an ethical imperative.
- Professional associations such as the NASW should take it upon themselves to advocate on behalf of excluded client populations such as African clans and cultural minorities such as white Afrikaners and Indians to achieve cultural relativity and overcome cultural domination.
- Recommendations on transformation of social work education, practice and research

The call for decolonization of social work in Africa has gained momentum and it is therefore prudent that all role players and interested groups should join hands to negotiate the form and content of a transformation agenda towards a decolonized social work profession. Thus, it is recommended that all parties get actively involved to decolonize the content and form of social work knowledge, space and practitioners. The following practical steps in social work practice, education and research are recommended:

- In practice involving African clans, it is recommended that social workers create relevance by either developing special approaches or techniques tailor-made for Africans or adapt the existing ones accordingly to become clan-centred. This, as a rule, would necessitate an adoption of a group rather than an individual focus in the helping process.
- It is further recommended that the provision of social support to African clans, should build on the inherent strengths and the characteristic existential conditions of the African clan system which functions in a collective and communalist manner contrary to the western individualistic approach.

- The cultural norms and values of African people, including principles of *ubuntu* and their belief in collectivism, complementarity, reciprocity and interconnectedness of everything provides important opportunities, support systems and resources that could be pooled for efficient and effective helping process. The African clan derived a great deal of strength in coping with challenges associated with raising children with DS from the clan's social support system, spirituality, strong moral grounds and *ubuntu* principle. Therefore, it is recommended that social work practice tap into all these as strengths and a strategic starting point when intervening in African clans' lives.
- In keeping with the strengths perspective, the phenomenological reflections around the unique African cultural practices including the unique clan relations based on reciprocity, complementarity, cooperation, harmony and spirituality were appreciated as assets and opportunities that must be harnessed when contemplating psychosocial support to Africans. All these may be important to consider when working with an African clan raising a child with DS. The significance of appreciating the essence of the phenomenological African clan system in its natural form and order as socially constructed by the African cultural thought and behaviour makes it possible for one to relate to and express the complexities of a multi-dimensional reality understood in African terms without imposing external influences. Thus, the social work profession can tailor its response to the challenges faced by African clans in a more culturally congruent and appropriate manner that is in tune with the African worldview. This approach is preferable to imposing a social order alien to the African cultural thought and behaviour.
- There is a need to create more opportunities for African clans raising children with DS to be involved in the helping process. This would be realized when a space for open communication can be promoted within the helping process with African clans. For social workers to do this effectively, they should be knowledgeable about the African clan system and its worldview. They should also learn and appreciate the significance of Afrocentric social work as well as associated values such as spirituality and affective helping. Additionally, qualities such as patience, tolerance and sympathy, mutuality, '*ubuntu*'/humanity, personal involvement that can translate into improved behaviour and attitudes when working with Africans needs to be infused in

social work education. Cognisant of the possibility of leadership challenges, lack of conducive and enabling organisational environment and processes and acknowledging that the above may hinder the implementation of Afrocentric social work, it is accordingly recommended that management buy-in be sought first before attempting to implement guidelines for Afrocentric social work. Such buy-in should include consideration of human and financial resources including time required to effectively implement the guidelines.

- In social work education and research, there is a need for a gradual shift from the hegemony of the Euro-North America epistemologies to embrace Afrocentricity. It is recommended that the decolonisation of the curriculum and research should be prioritised as it levels the playing field by asserting contextual factors. The decolonisation process will enable social work educators and researchers to transcend modern and post-modern conceptualisations in their scholarship enterprises and pursuit of real social change. Thus, to be effective, social work practice in Africa needs to shed its alien and foreign character and embrace Afrocentrism. While acknowledging diversity of the African clientele particularly in the light of the historical epistemicides and valuecides, it is necessary to promote cultural relativity instead of maintaining the current state of cultural hegemony of the Euro-North America. Often, this hegemony gets recycled in different forms and pretence including the promotion of cultural competency, equality, multi-cultural practices etc. Thus, decolonization remains an urgent project to undo the injustices of the past dispensation. It should be all-inclusive and cover decolonization of knowledge, power and being. These forms of decolonization should permeate social work education, practice and research.
- In light of the various issues unearthed by the empirical study pointing to lack of professionalism in practice, particularly in the DSD, there is a need for a serious relook at the professional standing of social work and its scope of practice to avoid it becoming obsolete. A national professional revitalisation campaign is recommended to be spearheaded by all relevant role-players including the SACSSP, NASWSA, ASASWEI, students formations as may exist nationally and perhaps in collaboration with regional and global bodies.

The main research question asked in this study was: “How can one use an understanding of the nature of the African family raising a child with DS, its experiences and coping mechanisms, and the opinions of social workers providing services to the family in order to develop indigenous social work practice guidelines for assisting such families in raising children with DS?”. The data presented in chapter 5 and the findings thereof answered this question beyond reasonable doubt. The researcher managed to develop an in-depth understanding of the identity, experiences, and coping mechanisms of African clans raising children with DS as well as the opinions of social workers assisting them. Through this understanding based on lived experiences, the researcher is able to talk about the clan system instead of the family as initially thought and perceived. On the basis of the findings and the understanding flowing from them, the researcher distilled the implications of such findings and used them to develop practice guidelines for social work practice when assisting the African clans raising children with DS. The researcher managed not only to develop practice guidelines, but to also identify key organisational factors that require attention for the guidelines to be effectively implemented and sustained.

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## 9. LIST OF ADDENDUMS

### **ADDENDUM A: A PREAMBLE TO AN INFORMATION AND INFORMED CONSENT DOCUMENT**

I, Mbazima Simeon Mathebane, the undersigned, am a doctoral student and lecturer in the Department of Social Work, University of South Africa (UNISA). In fulfilment of the requirements for a doctoral degree, I am undertaking a research project that carries the title: *Towards indigenised social work practice guidelines with African families raising children with Down syndrome.*

Accordingly, you will be informed in due course about the details of the research project and your potential involvement. I, therefore, take the opportunity to request your participation in the study. Please note that you can participate in the study either as an African family or member thereof, or as a social work practitioner serving African families. I will provide you with adequate information about the study including its aims and rationale so as to enable you to make an informed decision about whether to participate or opt out of the study. Additionally, you will also receive information about your involvement. This will include an indication of the kind of questions you will be asked in the study, specific things you will be asked to do during the course of the study, potential risks and benefits linked to your participation in the study, as well as your rights and responsibilities as a participant in the study.

The decision to undertake this research project was motivated by an identified and verified gap in the knowledge and practice of social work relating to African families raising children with DS. The case of African families raising a child with DS was identified as providing ample opportunities for in-depth knowledge of the unique character and coping mechanisms of African families. Thus, the aims of the study are as follows:

- To develop an in-depth understanding of the nature of African families, their experiences and their coping mechanisms when raising children with DS;
- To develop an in-depth understanding of the nature of social work services received by the African families whilst raising children DS;

- To develop an in-depth understanding of how African families would like to be supported by social workers with their experiences and coping strategies in relation to raising children with DS;
- To develop an in-depth understanding of the opinions of social workers regarding the level of congruence between their interventions and the self, experiences and coping mechanisms of African families; their suggestions for improvement of social work services to you; and
- To develop practice guidelines directed at social workers providing professional services to African families raising children with DS.

Remember that you can either participate as a member of an African family raising a child with DS or as a social worker. Should you decide to participate, you would be requested to participate in a semi-structured interview or a focus group interview that will be conducted at a suitable venue agreed upon between yourself and the researcher. If, as a member of an African family, you are the biological parent of the child with DS, where possible you may also be asked to participate in a focus group interview or, alternatively individual or one-on-one interviews.

Social workers rendering services to African families with a child with DS will be interviewed individually at a suitable venue and time agreed upon between themselves and the researcher. It is estimated that the interview will last approximately two hours. The questions that will be directed to you during the interview are attached as (annexure F1; F2 & G respectively).

As the research proceeds, you may be requested to do the following activities:

- Complete the schedule focusing on biographical information;
- Share your expectations regarding the whole project;
- Evaluate the value of the interview and to check if expectations are being addressed and by sharing the experiences gained; and
- Read through the verbatim transcriptions of the interviews to verify whether they are indeed a true reflection of the conversation.

With your permission, the interview will be audiotaped. The recorded interview will be transcribed word for word. Your responses to the interview (both the taped and the transcribed versions) will be kept strictly confidential. The audio tapes will be coded

to disguise any identifying information. The tapes will be locked in a safe in my private home and only I will have access to them. The transcript (without any identifying information) will be made available to my research promoter and an independent coder with the sole purpose of assisting and guiding me with this research undertaking. My research promoter and the independent coder will each sign an undertaking to treat the information shared by you in a confidential manner.

The independent coder is someone who is well versed and experienced in analysing information collected by means of interviews and is appointed to analyse the transcripts of the interviews independently to ensure that the researcher will report the participants' accounts of what has been researched. The audio tapes and the transcripts of the interviews will be destroyed upon the completion of the study. Identifying information will be deleted or disguised in any subsequent publication and/or presentation of the research findings.

Please note that participation in the research is completely voluntary. You are not obligated to take part in the research. Your decision to participate or not to participate will not affect you in any way now or in the future, and you will incur no penalty and/or loss of anything to which you may otherwise be entitled. Should you agree to participate and sign the information and informed consent document herewith, as proof of your willingness to participate, please note that you are not signing your rights away. If you agree to take part, you have the right to change your mind at any time during the study. You are free to withdraw this consent and discontinue participating without any loss of benefits. If, however, you do withdraw from the study, you will be requested to grant me an opportunity to engage in informal discussions with you so that the research partnership that we established can be terminated in an orderly manner. As the researcher, I also have the right to dismiss you from the study without regard to your consent if you fail to follow the instructions and if the information you have to divulge is emotionally sensitive and upset you to such an extent that it hinders you from functioning physically and emotionally in a proper manner. Furthermore, if participating in the study at any time jeopardises your safety in any way, you will be dismissed. Should I conclude that the information you have shared has left you emotionally upset or perturbed, I am obliged to refer you to a counsellor for debriefing or counselling (should you agree).

You have the right to ask questions concerning the study at any time. Should you have any questions or concerns about the study, please dial this number:

Please note that this study has been approved by the Research and Ethics Committee of the Department of Social Work at UNISA. Without the approval of this committee, the study cannot be conducted. Should you have any questions and enquiries not sufficiently addressed by me as the researcher, you are more than welcomed to contact the chairperson of the Research and Ethics Committee of the Department of Social Work at UNISA. His contact details are as follows: Prof. AH (Nicky) Alpaslan, Tel (012) 429-6739 or e-mail [alpasah@unisa.ac.za](mailto:alpasah@unisa.ac.za)

If , after you have consulted the researcher and the research and ethics committee in the department of social work at UNISA, their answers have not satisfied you, you might direct your questions/concerns and queries to the chairperson, Human Ethics Committee, College of Human Science, P O Box 392, UNISA, 0003. Based upon all the information provided to you above, and being aware of your rights, you are asked to give your written consent should you want to participate in this research study by signing and dating the information and consent form provided herewith and initialling each section to indicate that you have understood and agree to the conditions.

Thank you for your participation

.....

Mr. Mbazima Mathebane (Researcher)

083574 1571 or (012) 429-3854 or E-mail [mathems1@unisa.ac.za](mailto:mathems1@unisa.ac.za)

**ADDENDUM B: INFORMATION AND INFORMED CONSENT DOCUMENT**

Title of research project: **Towards indigenised social work practice guidelines with African families raising children with Down syndrome.**

Reference Number:

Principal investigator: Mr Mathebane Mbazima Simeon

Address: PO Box 27137, SUNNYSIDE, 0132

Contact telephone: 083 574 1571

DECLARATION BY OR ON BEHALF OF THE PARTICIPANT:	Initial
<p>I, _____ the _____ undersigned,                      .....(name),</p> <p>[ID no:.....] the participant or in                      my capacity as</p> <p>..... of the participant [ID                      no</p> <p>.....] of</p> <p>.....</p> <p>.....                      (address).</p>	
<p>A. HEREBY CONFIRM AS FOLLOWS:</p> <p>1. I/the participant was invited to participate in the above research project which is being undertaken by Mr. Mathebane Mbazima Simeon of the Department of Social Work in the School of Social Science, College of Human Science at UNISA.</p>	

<p>2. The following aspects have been explained to me:</p> <p>2.1 Aim: the study aims to develop an in-depth understanding of the nature of African families raising children with DS, their experiences and coping mechanisms so as to develop guidelines for indigenisation of social work practice with such families.</p> <p>The information will be used for the following:</p> <ul style="list-style-type: none"> <li>• To develop an in-depth understanding of the nature of African families, their experiences and coping mechanism when raising a children with DS;</li> <li>• To develop an in-depth understanding of the nature of social work services received by the African families whilst raising children DS;</li> <li>• To develop an in-depth understanding of how African families would like to be supported by social workers with their experiences and coping strategies in relation to raising children with DS;</li> <li>• To develop an in-depth understanding of the opinions of social workers regarding the level of congruence between their interventions and the felt needs and coping mechanisms of African families and their suggestions for improvement of social work services; and</li> <li>• To develop practice guidelines directed at social workers providing professional services to African families raising children with DS.</li> </ul>	Initial
<p>2.2. I understand that I am participating in this research project without any expectation of payment what so ever and that I will be interviewed either as a member of the African family (collectively as a family as well as individually and/or in focus groups were possible) about my experiences and perceptions about the family raising a child with DS and about the social work services received, or as a social worker providing services to the family raising a child with DS about my opinions regarding the level of congruence</p>	Initial

between social work practice and the self and experiences of African families raising a child with DS.	
2.3. Risks: As the researcher proceeds I may be emotional or too overwhelmed to handle some of the experiences that I will be sharing.	Initial
<ul style="list-style-type: none"> <li>• A possible benefit: As a result of my participation in this study, I will be afforded an opportunity to share my experiences and challenges as a member of an African family raising a child with DS or as a social worker rendering services to the families.</li> </ul>	Initial
<ul style="list-style-type: none"> <li>• Confidentiality: My identity will not be revealed in any discussion, description, or scientific publication by the investigators/researchers.</li> </ul>	Initial
<ul style="list-style-type: none"> <li>• Access to findings: Any new information/benefit that develops during the course of the study will be shared with me.</li> </ul>	Initial
<ul style="list-style-type: none"> <li>• Voluntary participation/refusal/discontinuation: My participation is voluntary. My decision about whether or not to participate will in no way affect me now or in the future.</li> </ul>	Initial
3. The information above was explained to me by Mr. Mathebane Mbazima Simeon in the language that I know proficiently and understand. I was given an opportunity to ask questions and all these questions were answered satisfactorily.	Initial
4. No pressure was exerted on me to consent to participate, and I understand that I may withdraw at any stage from the study without any penalty.	Initial
5. Participation in this study will not result in any additional cost to me.	Initial
<p>B. I HEREBY CONSENT VOLUNTARILY TO PARTICIPATE IN THE ABOVE PROJECT.</p> <p>Signed/confirmed at.....on .....2014</p> <p>.....</p> <p>Signature or right thumbprint of the participant</p> <p>.....</p>	

Signature or right thumbprint of witness	
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**ADDENDUM C: CONSENT FORM REQUESTING PERMISSION TO PUBLISH  
VERBATIM TRANSCRIPTS OF AUDIOTAPE RECORDINGS**

<p>As part of this project, I have made a photographic, audio and/or video recording of you. I would like you to indicate (with ticks in the appropriate blocks next to each statement below) which uses of these records you are willing to consent to. This is completely up to you. I will use the records only in ways that you agree to.</p>	<p>Tick next to the use of the record you consent to</p>
<p>1. The records can be studied by the research team and photographs/quotations from the transcripts made of the recordings can be used in the research report.</p>	
<p>2. The record (i.e photographs/quotations from the transcripts made of the recordings) can be used for scientific publication and/or presentations.</p>	
<p>3. The written transcripts and/or records can be used by other researchers.</p>	
<p>..... Signature of participant</p>	<p>Date:</p>
<p>..... Signature of Witness</p>	<p>Date:</p>

**ADDENDUM D: STATEMENT AND DECLARATIONS**

STATEMENT BY OR ON BEHALF OF RESEARCHERS

I, Mr. Mathebane Mbazima Simeon, declare that I have explained the information given in this document to .....(name of participant) or his/her representative ..... (name of representative), he/she was encouraged, and given ample time, to ask any questions. This conversation was conducted in the participant's language and no translator was used.

.....  
Signature of the researcher Date:

.....  
Signature of Witness Date:

## **ADDENDUM E: REQUEST FOR PERMISSION TO CONDUCT RESEARCH AT THE DOWN SYNDROME ASSOCIATION OF SOUTH AFRICA**

My name is Mr. Mathebane Mbazima Simeon. I am a lecturer and a part-time doctoral student in the Department of Social Work at the University of South Africa. In fulfilment of the requirements for the doctoral degree, I have to undertake a research project and have consequently decided to focus on the following research topic: **Towards indigenised social work practice guidelines with African families raising children with Down syndrome.**

The decision to undertake this research project was motivated by an identified and verified gap in the knowledge and practice of social work relating to African families raising a child with Down Syndrome. The case of African families raising a child with Down syndrome (DS) was identified as providing ample opportunities for in-depth knowledge of the unique character and coping mechanisms of African families. Thus, the aims of the study are as follows:

- To develop an in-depth understanding of the identity, the experiences and the perceptions of African families raising children with DS;
- To develop an in-depth understanding of the nature of social work services received by the African families whilst raising children DS;
- To develop an in-depth understanding of how African families would like to be supported by social workers with their experiences and coping strategies in relation to raising children with DS;
- To develop an in-depth understanding of the opinions of social workers regarding the level of congruence between their interventions and the nature of African families, their experiences and coping mechanisms when raising a child with DS and their suggestion for improvement of social work services; and
- To develop practice guidelines directed at social workers providing professional services to African families raising children with DS.

In view of the fact that your organisation work directly with children and parents of children with DS, as well as various role players involved, including social workers who provide support to the children and their families, I hereby approach you to

request your permission to conduct a study among African families raising a child with DS in your organisation.

The study will take a form of interviews which will last for about two hours with African families raising a child with DS. The families will be interviewed collectively as a unit and some family members, particularly the biological parents, will also be interviewed individually and in groups preferably using the existing support groups as organised by you at various areas or regions. As part of my ethical responsibilities, I am obliged to treat the participant with respect, not harm any of them, not force them to participate, to inform them about the practical details of the study, and to treat any information provided to me as confidential. Participants will sign a consent form through which they will be informed about the study in detail and through which I, as a researcher, will be committing myself to the ethical principles. Granting permission to conduct this study will, therefore, contribute towards closing the gap of knowledge regarding self of the African family raising a child with DS, their challenges, and their coping mechanisms which will then be used to develop guidelines for the indigenisation of social work practice in South Africa.

Thanking you in advance

Yours faithfully,

Mr. Mathebane Mbazima Simeon (Researcher)

083 574 1571 or (012) 429-3854

E-mail: [mathems1@unisa.ac.za](mailto:mathems1@unisa.ac.za)

**ADDENDUM F1: THE INTERVIEW GUIDE (AFRICAN FAMILY RAISING A CHILD WITH DS)**

- 1. Can you please tell me about your family?**
- 2. Please tell me more about your experiences of caring for a child with DS as a family?**
- 3. Lets talk about your coping mechanisms....**
- 4. Please tell me about the services you received from a social worker? Please elaborate on how these services assisted you and what you found to be inadequate based on your needs**
- 5. How would you like to be assisted by social workers in a culturally sensitive manner?**

## **ADDENDUM F2: THE INTERVIEW GUIDE (SOCIAL WORKERS)**

- 1. What is your experience of working with African families raising children with DS?**
- 2. What is your opinions regarding the level of congruence between the services you render and the nature of African families, their experiences and coping mechanisms when raising children with DS?**
- 3. What would you suggest for the improvement of social work service to African families raising children with DS?**

## **ADDENDUM G: THE FOCUS GROUP PROMPTS**

- 1. Let us have a discussion about your families...**
- 2. Let us talk about your experiences of caring for a child with DS as a family...**
- 3. Let us talk about your coping mechanisms...**
- 4. Please tell me about the services you received from a social worker...**
- 5. Please share your suggestions about how you would you like to be assisted by social workers in a culturally sensitive manner?**

## ADDENDUM H1: BIOGRAPHICAL INFORMATION (African families)

Item	Details
Participant code:	
Relationship to the child with DS	
Age and gender of the child with DS	
Gender of participant	
Age	
Membership of a support group (if 'yes', which one)	
Ethnic group	
Location (Urban or rural)	
Place of residence	

**ADDENDUM H2: BIOGRAPHICAL INFORMATION (Social Workers)**

Item	Details
Employment sector:	Government or None-Governmental organisation
Social work rank	
Gender	
Duration in service	
Duration of service to families of children with DS	
Links with DS support groups (if yes, which one)	
Ethnic group	
Location (Urban or rural)	
Place of residence	

**ADDENDUM I: ETHICAL CLEARANCE**

**NOTICE TO POSTGRADUATE QUALIFICATIONS SECTION (M&D)**

**RESULT : MODULE IN RESEARCH METHODOLOGY**

<b>STUDENT NAME</b>	<b>MATHEBANE MS</b>	<b>STUDENT NUMBER</b>	<b>32711905</b>
<b>DEGREE</b>	<b>D PHIL</b>	<b>SPECIALISATION</b>	<b>Social Work</b>
<b>Please indicate the relevant option with an x:</b>			
A. The above student <u>did not comply</u> with the requirements for the module in Research Methodology and <u>may reregister</u> for the module			
B. The above student <u>did not comply</u> with the requirements for the module in Research Methodology and <u>may not continue with his studies</u> for the ..... degree. <i>Please provide reasons . . .</i>			
C. I confirm that the above student complied with the requirements for the module in Research Methodology (MPCHS91)(Submitted an acceptable research proposal) and may now proceed to register for the research component. <i>Please provide details below</i>			<b>X</b>
<b>Title : Towards indigenous social work practice guidelines for assisting African families raising children with Down Syndrome</b>			
<b>Supervisor : Dr J Sekudu</b>		<b>Personnel Number: 90191277</b>	
<b>Highest Qualification: D Phil in Social Work (UP)</b>			
<b>Co-supervisor: N/A</b>		<b>Personnel Number:</b>	

**Highest Qualification: D.Phil. (Social Work) UP**

**Address, if external : N/A**

**(including email )**

**Additional comments:**

**Approval (CoD) Approved.**

**Comments: The final research proposal was reviewed in compliance with the Unisa Policy on Research Ethics by the Department of Social Work's Research Ethics Review Committee on 17 July 2014 and approval was granted for the duration of the project. (Ethics Approval Ref # DR&#C\_2014\_005)**

**Signature:**



**Prof AH Alpaslan**

**Date: 3 November 2014**

**Comments:**

**Signature :**

**On behalf of College/School Executive Committee**

**Date:**

**FOR OFFICE USE ONLY BY SECTION:  
PG QUALIFICATIONS**

**Result captured (F375)**