

**Exploring the relationships between perceived social support, stress and well-being of grandparents raising a grandchild with a congenital disability**

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### **Dedication**

This thesis is dedicated to all the grandparents (grandmothers and grandfathers) who are the safety net of our society and who live day by day in love and understanding for their grandchild and family, even when the times are hard.

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## Abstract

The increase in grandparents who take on the role of raising their grandchild has incited a growth in research, specifically on how this population is able to accomplish such an important responsibility at the later years of their life. However, not much is known about grandparents who are raising grandchild with a congenital disability. Grandparents may take on this role as either a co-parent or as a sole parent out of obligation towards their grandchild and their family. Grandparents from low socio-economic settings with corresponding challenging family and environmental circumstances are a particularly vulnerable group. As a result, these grandparents may experience heightened levels of stress, lower levels of well-being and increased social isolation, which may have a negative influence on their grandchild's developmental outcomes. This thesis will focus on a study undertaken that aimed to explore the relationships between stress, well-being and the perceived needs for and helpfulness of available social support of grandparents raising their grandchild with a congenital disability. A total of 50 sole-parenting and co-parenting grandparents from various areas in the Western Cape took part in this adapted survey design in the form of structured interviews. An expected inverse relationship was found between caregiving stress and well-being. A further expected positive relationship was found between the grandparents' perceived needs for types of support and their well-being, and, as hypothesised, an inverse relationship was identified between the grandparents' perceived need for types of support and their stress. With further analysis, perceived need for types of support positively mediated the stress and well-being. Together with its clinical implications, this study also provides understanding regarding the implications of applying measures devised on foreign populations to the current South African context.

*Keywords:* disability, grandchild, grandparents, perceived social support, raising, stress, well-being

## Opsomming

Die toename in grootouers wat hul kleinkinders grootmaak, het gelei tot 'n groei in navorsing, spesifiek oor die wyse waarop hierdie populasie in staat is om so 'n belangrike en verantwoordelike rol op hul ouderdom te vervul. Daar is egter nie veel bekend oor grootouers wat kleinkinders met 'n aangebore gestremdheid grootmaak nie. Grootouers vervul hierdie rol óf as 'n mede-ouer, óf as 'n alleenouer, uit verpligting teenoor hul kleinkind en hul familie. Grootouers uit lae sosio-ekonomiese agtergronde, met ooreenstemmende uitdagings ten opsigte van familie- en omgewingsomstandighede, is veral 'n weerlose groep. Die resultaat hiervan is dat sodanige grootouers verhoogde stresvlakke, laer welstandsvlakke en verhoogde sosiale isolasie mag ervaar, wat kan lei tot 'n negatiewe uitwerking op hul kleinkinders se ontwikkelingsuitkomst. Hierdie studie verken die verhoudings tussen stres, welstand en die waargenome behoeftes na beskikbare maatskaplike ondersteuning (en of hierdie ondersteuning van waarde is) vir die grootouers wat hul kleinkind met 'n aangebore gestremdheid grootmaak. 'n Totaal van 50 grootouers (alleen- of mede-ouers) vanuit verskeie gebiede in die Wes-Kaap het deelgeneem aan hierdie aangepaste meningsopname-ontwerp in die vorm van gestruktureerde onderhoude. 'n Verwagte inverse verhouding tussen versorgerstres en welstand is bevind. 'n Verdere verwagte positiewe verhouding is bevind tussen die grootouers se waargenome behoeftes na tipes ondersteuning en hul welstand en, soos veronderstel, is 'n inverse verhouding geïdentifiseer tussen die grootouer se waargenome behoeftes na tipes ondersteuning en hul stres. Met verdere analise, het waargenome behoeftes na tipes ondersteuning, die verhouding tussen stres en welstand, positief met bemiddeling. Tesame met die kliniese implikasies, verskaf hierdie studie ook begrip rakende die implikasies van die toepassing van maatreëls wat ontwerp is vir populasies wat nie met die huidige Suid-Afrikaanse konteks ooreenstem nie.

*Sleuteltermes:* gestremdheid, kleinkind, grootouers, waargenome maatskaplike ondersteuning, versorgers, spanning, welstand.

# **Chapter 1: Problem Statement and Rationale**

## **1.1. Introduction**

This chapter outlines the research problem addressed in the study and highlights the significance and relevance of the study. First, the problem statement and the rationale for the study are provided. Next, the chapter offers a list of important and frequently used terms and definitions. This is followed by a list of abbreviations and acronyms. The chapter concludes with an overview of the seven chapters of the thesis.

## **1.2. Rationale and Problem Statement**

Grandparents are increasingly required to play an active role in the raising of their grandchildren, both internationally (Du Preez, Richmond, & Marquis, 2015; Kim, Kang, & Johnson-Motoyama, 2017) and in South Africa (Dolbin-Macnab et al., 2016; Lehohla, 2011). Family compositions are evolving to include grandparents as either co-parents or as primary caregivers of their grandchild (Kim et al., 2017). Co-parenting grandparents live in the same household as the grandchild and participate in the informal childcare and caregiving routines of raising the grandchild with at least one parent of the grandchild (Kirby & Sanders, 2012). Grandparents as co-parents settle into this role when they provide support to the parent of the grandchild by helping them raise the grandchild (Buchanan & Rotkirch, 2018). In some instances, the grandparent can also be a co-parent with another family member, such as, the grandparent's spouse or aunts or uncles, in the absence of either parent of the grandchild (Sharda, Sutherby, Cavanaugh, Hughes, & Woodward, 2019).

Grandparents who carry out the parenting roles and caregiving routines as part of their responsibility of raising their grandchild in the absence of the parent of the grandchild have in literature been referred to, among other terms, as primary caregivers (Du Preez et al., 2015), custodial grandparents (Taylor, Marquis, Coall, Batten, & Werner, 2017) or kinship caregivers (Sharda et al., 2019). However, to highlight the full-time parenting and caregiving roles which the grandparents undertake, the current study uses the term "parenting grandparents". Furthermore, the current study uses the term "sole-parenting grandparents" to refer to grandparents who are raising their grandchild in the absence of the parent of the grandchild.

In South Africa, the labour migration, which originated from the apartheid system, has resulted in a greater dispersion of families, with parents' being forced to move to other provinces to find employment (Schatz, Madhavan, Collinson, Gómez-Olivé, & Ralston, 2015). This labour migration may leave the grandparents to take on the role of raising their grandchildren (Schatz et al., 2015). However, the partial or entire disruption of a parent's ability to fulfil their caregiver responsibility has also been suggested to be due to reasons such as substance abuse and mental health problems (Gordon, 2018), teenage pregnancy (Samuels, 2013), incarceration, child abuse or neglect (Choi, Sprang, & Eslinger, 2016) or death of one or both biological parents (Cox, 2014; Hayslip, Blumenthal, & Garner, 2014; Njororai & Njororai, 2013).

In most cases, co-parenting grandparents take on this responsibility as an informal agreement with the parents of the child (Kirby & Sanders, 2012). However, sole-parenting grandparents usually take on caregiving due to the sudden non-involvement of the parent of the child such as when the parent dies (Gordon, 2018). In some instances, the sudden non-involvement of the parent of the child may reduce the possibility of ensuring timely legal proceedings to transfer the custody of the grandchild to the grandparent (Neely-Barnes & Dia, 2008). This legal barrier may prevent the grandparent's access to necessary financial aid and necessary social services needed to raise their grandchild (Neely-Barnes & Dia, 2008).

According to the South African Statistics of Older Persons (2014), low levels of literacy are prevalent among the older population. Approximately 45 per cent of the elderly population are unable to write their own name or count their money during business transactions, and more than half of the population of South African elderly are further unable to fill in forms or access information from a newspaper or a book (aStatistics South Africa, 2014). Therefore, the low literacy of the grandparents may reduce their access to financial aids, because of possible challenges in completing the necessary paperwork for the legal procedures (aStatistics South Africa, 2014).

Statistically, it has been suggested that, globally, approximately 163 million grandparents are raising their grandchild (Dolbin-MacNab & Yancura, 2017; Leinaweaver, 2016), with parenting grandparents noted across countries such as China, Romania (Dolbin-MacNab & Yancura, 2017), Philippines, England, Wales, Finland, Australia, the United States of America (Buchanan & Rotkirch, 2018), New Zealand (Gordon, 2018) as well as in South Africa. According to the South African Census 2011, there has been a rise in households

headed by elderly persons, from 1.7 million in 1996 to approximately 2.9 million households in 2011.

The 2014 South African household survey has shown that 4.9% of children in South Africa (from the age of 5 years and older) have been classified as having a disability (Lehohla, 2011). Within the Western Cape, approximately 3,000 children have been identified to have severe to profound intellectual disability (Spangenberg et al., 2016). While there is a known statistical rise of parenting grandparents in South Africa, there is still a lack of recognition of this population. There is a further absence of statistical data of the prevalence of grandparents who are raising their grandchild with a disability in South Africa. Additionally, despite the interest in research on parenting grandparents, this field has remained underdeveloped, especially within the context of grandparents raising their grandchild with a congenital disability. Studies on this specific population of parenting grandparents have generally focused on the grandparent's role in providing emotional and instrumental support to the parent of the grandchild (Lee & Gardner, 2010; Mitchell, 2007) or have highlighted the grandparent's perspectives of the disability of their grandchild, without being directly involved in caregiving or parenting (Woodbridge, Buys, & Miller, 2009b).

Compared to acquired childhood disabilities, congenital disabilities have been indicated to bring about a greater amount of stress to the caregiver. Adjustments to the parenting styles and the family dynamics are required from the birth of the child (Benson, Gross, Messer, Kellum, & Passmore, 1991; Tak & McCubbin, 2002). In the case of grandparents raising their grandchild with a congenital disability, they have been shown to be vulnerable, due to the heightened levels of stress they experience, compared to grandparents raising their grandchild without a disability (Kresak & Gallagher, 2014). The vulnerability of parenting grandparents has been associated with factors such as understanding and managing their grandchild's congenital disability regarding the amount of hands-on care required daily by the grandchild (Janicki, McCallion, Grant-Griffin, & Kolomer, 2000). Grandparents may also experience further vulnerability due to environmental factors, such as family conflicts, financial strains related to poor employment rates and disability-related financial costs (Hillman & Anderson, 2019). Additional environmental risks may also include limited access to optimal housing and inadequate infrastructures (Brown et al., 2017) as well as violence within the grandparent's community (Longoria, 2009). Grandparents may also be potentially vulnerable due to innate characteristics, such as progressive age-related physical limitations

and age-related health challenges (Hanass-Hancock & Casale, 2014). As grandparent caregivers age, they may experience more fatigue and distress linked to the increased time and energy required for daily parenting and caregiving (Kresak, 2012).

Grandparents may also experience social isolation and this has been linked to increased time and energy required in raising their grandchild with a disability as well as the lack of reliable respite, which leaves little opportunity for social interaction (Force, Botsford, Pisano, & Holbert, 2000; Park, 2009). Parenting grandparents may also experience isolation from their age-related peers, which may further contribute to the risk of them being less likely and less willing to reach out for help and support even when they have the need for it (Janicki et al., 2000).

However, grandparents also possess various opportunity factors which make them successful as parents when raising their grandchild with a congenital disability. For example, they have previous parenting experience to draw from, having gained life experience and wisdom (Hillman & Anderson, 2019). The intergenerational gap further strengthens the grandparent's competencies (Downie, Hay, Horner, Wichmann, & Hislop, 2010) and provides them with opportunities to pass on family connections and memories to their grandchild (Tang, Jang, & Copeland, 2015). These various opportunity factors are essential resources which become crucial coping mechanisms in challenging times. However, research has shown that these various opportunity factors may be suppressed when the challenges related to their grandchild's disability magnify (Force et al., 2000) and when they are socially isolated from those around them (Mhaka-Mutepfa, Cumming, & Mpofu, 2014). The ways in which co-parenting and sole-parenting grandparents experience the challenges when raising their grandchild with a disability have been linked to the onset of their parenting responsibility, the family circumstances in which they take on this responsibility as well as their own personal way of dealing with the disability of their grandchild (Janicki et al., 2000). These varied parenting experiences of co-parenting and sole-parenting grandparents have been indicated to contribute to stressors which may influence their well-being (Barnett, Loriena, Wilmoth, & Sano, 2016; Dolbin-MacNab & Yancura, 2017).

While the nature of challenges accompanying the grandchild's disability are known to influence the family's lifestyle (Kresak & Gallagher, 2014), additional circumstances, such as a lack of financial resources, may further impact the well-being of the grandparent (Kresak & Gallagher, 2014). However, from the available studies on grandparents raising their

grandchild with a disability (Brown et al., 2017; Gallagher, Kresak, & Rhodes, 2010; Gardner, Scherman, Efthimiadis, & Schultz, 2004; Hillman & Anderson, 2019; Kresak et al., 2014; McCallion et al., 2004), there is currently a paucity of research that examines the physical and emotional well-being of grandparents raising their grandchild with a congenital disability. In fact, the physical and emotional well-being of these grandparents has been defined as a “balance point between an individual’s resource pool and the challenges faced” (Dodge, Daly, Huyton, & Sanders, 2012, p. 230). Therefore, when the challenges overpower the resources available to the grandparents, there is a greater risk for low levels of well-being (Dodge et al., 2012).

The physical and emotional well-being of parenting grandparents plays a crucial role in determining the developmental outcomes of the grandchild (Mhaka-Mutepfa et al., 2014), especially when the grandchild’s disability becomes more challenging as the grandchild grows and develops (Gardiner, Miller, & Lach, 2018; Kim & Chung, 2016). As a result, challenges become sources of stress which may persist and intensify to evolve into distress. Grandparents who are in a state of distress may have reduced responsivity to their grandchild (McConnell & Savage, 2015), reduced coping abilities and reduced enjoyment of daily living (Bailey et al., 2006). Therefore, it is crucial to decrease the stress experienced by the parenting grandparent for positive developmental outcomes of their grandchild. Social support has been considered in research to be important protective factors for a caregiver or parent to draw on from their environment (Benzies & Mychasiuk, 2009; Guralnick, 1998).

While research on the protective qualities of social support has been widely documented for vulnerable families (Benzies & Mychasiuk, 2009), only a handful of studies specifically investigate how social support benefits grandparents raising their grandchild with a disability. These grandparents have been identified as showing improvements to their well-being, coping strategies (Kresak & Gallagher, 2014) and positivity adaptation (Hayslip et al., 2014) due to support they received from their adult child, their friends and their relatives. Social groups have also been found to contribute to higher levels of well-being and more enjoyment of life of the parenting grandparent, due to their feelings of increased sense of belonging and increased self-esteem (Mhaka-Mutepfa et al., 2014). These findings indicate that social support can potentially reduce the effects of stress with reduced depression, with less caregiver role strain and better levels of health among parenting grandparents (Sharda et al., 2019).



However, in order to identify and understand the function of social support for grandparents raising their grandchild with a disability, there is a need to better define this construct. Theorists (Barrera, 1986; Lakey & Cohen, 2000; Sarason & Sarason, 2009) who have zoomed in on the characteristics and functional properties of social support have highlighted the need for research to clearly define what variables of social support are relevant to the context in which it is being measured. Past studies have referred to social support either as a global construct or in terms of its variables, such as sources of support or needs for support, or effects of social support for grandparents. However, in relation to mental health, social support has been found to have a significant relationship to stress and well-being when it is in the form of perceived social support. Perceived social support refers to the type and amount of support (Vangelisti, 2009) and the helpfulness of the support (Barrera, 1986) the individual perceives to be available to them.

To date, there has been no research which has identified the relationship between stress and well-being in the presence of perceived social support for grandparents raising a grandchild with a congenital disability. In an environment where there is a risk that the needs may be unmet or the support provided may be unhelpful (Vangelisti, 2009), it is important to analyse the construct of perceived social support as perceived needs for types of support and as perceived helpfulness of the available support. The analysis of perceived social support will provide a required understanding of whether this form of social support may sustain the well-being of grandparents who raise their grandchild with a congenital disability.

Furthermore, most studies have been conducted on literate individuals, often excluding the voices of those with low literacy. The current study therefore sought to include grandparents of low literacy (Research Center Survey, 2016). In addition, the current study has also included the voices of an under-researched population in the South African context, namely, the isiXhosa speaking grandparents raising a child with a disability (Brock-Utne, 2015).

### **1.3. Terminology**

The following terms are defined as they are used frequently in this study.

#### **Congenital disability**

This term refers to any form of disability which is present before birth or from birth of the child (World Health Organization, 2010). According to the World Health Organization

(WHO), congenital disabilities relate to genetic or physical malformations, metabolic disorders as well as functional disorder present when the child is in the womb or at birth. Examples of such disabilities include cerebral palsy, developmental disabilities, autism, foetal alcohol syndrome, intellectual disabilities, hearing impairment, visual impairment or genetic syndromes, such as Down syndrome (Lee, 2013).

## **Construct**

A construct is defined as a theoretical concept or an abstract phenomenon (Kimberlin & Winterstein, 2008). In the current study, three main constructs that were measured are caregiving stress, the well-being of the grandparent caregiver as well as the perceived social support, measured as the perceived helpfulness of available support, and the perceived need for types of support.

## **Co-parenting grandparent**

Co-parenting grandparents refer to grandparents who live with at least one biological parent of the grandchild and who share the parenting and caregiving responsibilities of raising their grandchild (Barnett et al., 2016).

## **Grandparent-headed households**

Within the current study, a grandparent-headed household is defined as a household which is run by a parenting grandparent in the absence or minimal involvement of the parent of the grandchild (cStatistics South Africa, 2014).

## **Emotional well-being**

Emotional well-being refers to the affective component of well-being, with a focus on the affective and emotional responses of the individual, such as happiness, feelings of depression or anxiety, as well as life satisfaction (Lamers, Bolier, Westerhof, Smit, & Bohlmeijer, 2012). In the current study, the emotional well-being of the parenting grandparents relates to the various affects and feelings linked to raising their grandchild with a disability.

## **Grandparent-grandchild dyad**

This term refers to the interaction between the parenting grandparent and their grandchild contextually adapted from the term “parent-child” interaction as used by Guralnick (2011).

### **Parenting grandparents**

Parenting grandparents are those grandparents who raise their grandchild to fulfil both parenting roles, as well as the daily caregiving activities which qualify as formal care and full-time caregiving for their grandchild (Hanass-Hancock & Casale, 2014). Parenting grandparents may be either a co-parent or a sole parent to their grandchild with a disability. For the parenting grandparent in this study, caregiving is defined as the act of performing physical activities, which daily require time and energy, for the grandchild (Hanass-Hancock & Casale, 2014). These daily activities include the preparation of food for the household, washing and bathing, attending medical and school appointments with the grandchild and ensuring that the grandchild has access to appropriate healthcare activities, such as provision of medication and treatment of injuries (Hanass-Hancock & Casale, 2014).

### **Perceived helpfulness of available support**

Perceived helpfulness of available support refers to the appraisal of how helpful the various available sources of support may be to the individual (Vangelisti, 2009). These sources may be informal or formal sources of support. Informal sources of support to parenting grandparents may include spouse/partner support, family or neighbours, while formal sources of support may be in the form of agency services, support groups and professional services (Guralnick et al., 2008).

### **Perceived need for types of support**

This term is defined as the grandparent's perception of what types of support they need or require when raising their grandchild with a congenital disability (Trivette, Dunst, & Hamby, 2010). These types of support may include emotional, information, practical, financial or childcare support (Fuentes-Peláez et al., 2014).

### **Perceived social support**

Perceived social support refers to the qualitative variable of the meta-construct of social support and is defined as the appraisal of the support which the grandparent receives (Barrera, 1986; Vangelisti, 2009) or expects to receive in times of need (Siedlecki, Salthouse, Oishi, & Jeswani, 2014) when raising their grandchild with a congenital disability. The term

“perceived social support” is used in the current study as an umbrella term to encompass the perceived need for types of support and perceived helpfulness of available support.

### **Physical well-being**

This term refers to the physical functioning of an individual, with specific reference to the absence or presence of physical health conditions when faced with stress (Thoits, 2010). In the current study, the physical well-being of parenting grandparents refers to the physical expense of energy in raising their grandchild with a disability or the resultant health status of the grandparent in the context of challenges they experience when raising their grandchild with a disability.

### **Social support**

Social support is a multi-dimensional construct (Vangelisti, 2009) which, in the context of parenting grandparents, is defined as the support provided by the social ties that are known to and available to the grandparent in their times of need (Kresak, Gallagher, & Kelley, 2014). Social support has also been defined as a meta-construct that is comprised of sub-constructs such as perceived social support or received social support (Haber, Cohen, Lucas, & Baltes, 2007).

### **Sole-parenting grandparent**

In the current study, the term “sole-parenting grandparents” refers to grandparents who have taken on the parenting and caregiving roles to raise their grandchild, due to the absence of the biological parent of the grandchild (McCallion et al., 2004).

### **Stress**

Stress refers to the emotional responses of the grandparent which arise as a result of attempts of the grandparent to adapt to the various demands of parenting and caregiving. These demands may become challenges which create moments of anxiety together with a perceived lack of control of the situation in the grandparent, which results in the stress they experience (Dolbin-MacNab & Yancura, 2017; Hutchison, Feder, Abar, & Winsler, 2016).

## **Well-being**

Well-being is defined as the balance between the available resources of an individual and the challenges they experience (Dodge et al., 2012). It is also defined as a multi-dimensional construct which encompasses the positive physical and emotional functioning of an individual (Lamers et al., 2012).

### **1.4. Abbreviations**

CSPID	:	Children with Severe to Profound Intellectual Disabilities
DSA	:	Developmental Systems Approach
ECI	:	Early Childhood Intervention
FSS	:	Family Support Scale
PSS	:	Parental Support Scale
PWBI	:	Personal Well-Being Index
QoL	:	Quality of Life
SFS	:	Support Functions Scale
NGO	:	Non-Governmental Organisation
WHO	:	World Health Organization

### **1.5. Outline of Chapters**

The current study is presented in a total of seven chapters.

Chapter 1 consists of the problem statement and rationale for the study, with the definitions of the most used terminologies and abbreviations in the study.

Chapter 2 describes the population of grandparents who are raising their grandchild, either as a co-parent or as a sole parent. The conceptual framework of the Developmental Systems Approach (DSA) (Guralnick, 2011) is presented in the context of available literature on parents raising a child with a congenital disability to set the assumptions for the grandparent context of the current study. Following this, a systematic search and review are presented specific to the research which has been published on grandparents raising their grandchild with a congenital disability. The various studies are compared and investigated in terms of the relationships between stress, well-being and social support constructs which relate to the current study. This follows an in-depth review of literature regarding the construct of stress, well-being of grandparents and social support. The literature is further described in terms of

the perceived social support as a construct of social support. The chapter concludes with the available parenting literature regarding the documented mediating and moderating effects of perceived social support on stress and well-being to make assumptions for the context of grandparents raising their grandchild with a disability.

Chapter 3 describes Phase 1 of the study, which involves the identification and selection processes of the four measures, namely the Parental Stress Scale (PSS), the Personal Well-Being Index (PWBI), the Support Functions Scale (SFS) and the Family Support Scale (FSS). Within this same chapter, Phase 2 of the study is described, where details are provided regarding the various adaptations that were made to the four measures in terms of the content and context modifications. Thereafter, the translation process of the materials from English to isiXhosa and Afrikaans is presented. The chapter ends with a description of the adaptations which were made to the measures with graphic symbols.

Chapter 4 discusses the methodology of Phase 3 of the study, beginning with the main aim, sub-aims and the hypotheses set out for the study. The research design of the study is then described, followed by details about the participant recruitment as well as the sampling method, participant selection criteria and the description of the participants who took part in the study. The two pilot studies which were carried out are described, followed by their outcomes. A detailed description is further provided regarding the research assistants who assisted with the study, followed by the materials used in the study. This was followed by the ethical considerations and the general procedures for data collection. The chapter then concludes with details regarding the procedures for the data preparation and what form of data analysis would be used, whereafter the procedural reliability which was carried out is discussed.

Chapter 5 contains the results of the data collected as part of the study. The chapter begins with a description of the reliability of the measures, which includes the reason for excluding the FSS from further analysis. Following this, the descriptive statistics for each item of the three remaining measures (the PSS, PWBI and the SFS) are described. Thereafter, the re-evaluated hypotheses are provided, as a result of the excluded FSS measure. The analysis of the statistical correlations between perceived need for types of support, stress and well-being are described. This follows with the analysis of the mediating and moderating effects of perceived need for types of support on the relationship of stress and well-being. The chapter concludes with the statistical analysis of the correlations between the stress, well-being and

perceived need for support on the grandparents' reported demographic variables of type of grandparent, age of grandparent, monthly household income and perceived financial status.

Chapter 6 is the discussion chapter where the various results of the study are interpreted and discussed in detail with a comparison and contrast to previous research. The results specific to the validity of the measures used in the study are interpreted. The findings of each of the constructs of stress, well-being and perceived need for types of support are further interpreted and discussed in light of past research. Following this, the relationships between caregiving stress, well-being and perceived need for types of support are discussed in the context of the grandparents raising their grandchild with a congenital disability. The chapter then discusses the mediating and moderating effects of perceived need for types of support on the relationship of caregiving stress and well-being that were found. The implications for these findings are discussed in line with past research.

Chapter 7 is the concluding chapter. A summary of the findings is provided as well as the clinical implications of the findings of the study. The strengths and limitations of the study are then provided, followed by the recommendations for future research.

## **1.6. Summary**

This chapter presented an overview of the problem statement and the rationale for the current study specific to the need for research on the population of grandparents raising their grandchild with a congenital disability. The chapter also offered a rationale for the need for research specific to explore the combination of the constructs of perceived social support and its influences on caregiving stress and grandparent well-being. The descriptions of the abbreviations and definitions of the essential terminologies used throughout the study were given. Finally, a summary of each chapter was provided.

## Chapter 2: Literature Review

### 2.1. Introduction

The aim of Chapter 2 is to provide a background of grandparents raising their children in general and, more specifically, grandparents raising their grandchild with a disability. A systematic search of the literature on grandparents raising their grandchild with a disability is described. The aim is to provide an understanding of the past research on this population, specifically regarding the relationships between the three main constructs of stress, well-being and social support. Following this, the available literature on the mediating and moderating effects of perceived social support on the stress and well-being is brought forward.

### 2.2. Parenting Grandparents

Family structures have undergone significant change during the past century, where many nuclear families have transformed to give rise to greater grandparent involvement in the raising of their grandchild (Buchanan & Rotkirch, 2018). Grandparents can therefore also fulfil daily physical caregiving activities. These include food preparation for the household, washing and bathing, helping with school homework, attending medical and school appointments with the grandchild and ensuring that the grandchild has access to appropriate healthcare activities, such as the provision of medication and treatment of injuries (Hanass-Hancock & Casale, 2014). However, raising a grandchild also involves the practices around parenting the grandchild. This includes using parenting styles and parenting practices, as well as decision-making, which are all influenced by cultural values and practices transmitted from generation to generation (Hutchison et al., 2016). Therefore, in the context of the current study, parenting grandparents are those who are raising their grandchild by fulfilling the daily parenting and caregiving functions to contribute to their grandchild's developmental outcomes (Dolbin-MacNab & Yancura, 2017).

Parenting grandparents may raise their grandchild by being either a co-parent or a sole parent. A co-parenting grandparent shares the daily caregiving role with at least one of the biological parents of the grandchild often in the same household (Samuels, 2013). On the other hand, as a sole parent, the grandparent raises the grandchild in the absence of the parent of the child (Schatz et al., 2015).



The advantage of having grandparents as the next alternative parent for the grandchild has been increasingly recognised in research, especially for children who come from traumatic backgrounds, for example having experienced neglect, abuse or violence (Gordon, 2018). Grandparents can play an important supportive role in changing these traumatic experiences related to separation, abandonment and breakdown of trust in the grandchild to a future of resilience with positive emotional and social developmental outcomes (Lee, Blitz, & Srnka, 2015). The biological link between the grandparent and the grandchild represents a source of stability, attachment and cultural identity which act as protective factors for the grandchild (Tang et al., 2015). Studies have suggested that a nurturing and protective environment provided by grandparents can lead to better mental health and pro-social behaviour in the grandchild (Buchanan & Rotkirch, 2018; Downie et al., 2010).

Research has indicated that previous parenting knowledge, experience and wisdom are useful when having to parent a second time around (Dolbin-MacNab & Yancura, 2017). These strengths can contribute to grandparents' efficacy, self-confidence and understanding that they are not alone in their situation (Hayslip, Fruhauf, & Dolbin-MacNab, 2017). These personal strengths have been indicated to contribute to the grandparent's coping mechanisms and their efficiency in problem-solving, which in turn influences healthy decision-making to achieve their targeted life goals (Hayslip, Fruhauf et al., 2017). The effect of these positive skills can lead to the empowerment of parenting grandparents, with resultant competent and compassionate caregiving and an optimum quality of care for the grandchild (Hayslip, Fruhauf et al., 2017). Most importantly, however, these strengths are crucial when challenges and stressors arise when raising a grandchild.

### **2.2.1. Challenges of raising a grandchild**

Despite the fundamental advantages which exist for the grandchild, there has been increased recognition of the challenges accompanied with grandparents' role of raising a grandchild (Hayslip, Fruhauf et al., 2017). The literature has indicated that parenting grandparents' late onset of parenting in their life may bring about challenges in the form of financial strain (Hayslip, Fruhauf et al., 2017), family conflicts and social isolation (Choi et al., 2016). Furthermore, grandparents who spend more than 30 hours a week in caregiving may have lower positive health outcomes than those who spend less time in caregiving (Glaser, Di

Gessa, & Tinker, 2014). Literature suggests that intensive caregiving may be associated with the grandparent's disadvantaged health situation (Glaser et al., 2014).

Instances where grandparents become parents may be coupled to socio-economically disadvantaged communities and due to various social ills which prevent the biological parent from raising their child (Hanass-Hancock & Casale, 2014). The socio-economic strains may be deepened due to further expenses which are required for the grandchild's clothing, school supplies, food and other expenses which accompany caregiving (Testa, 2013). It has also been indicated that, in South Africa, lack of employment opportunities can contribute to the grandparent's struggle to provide the basic necessities for their grandchild (Dolbin-Macnab et al., 2016). Financial strains can be further deepened in instances where grandparents also have to provide for their adult child living in the same household (Kirby & Sanders, 2012). In some families in South Africa, it is culturally and traditionally expected of grandparents to help raise the younger children in the family during times of need (Dolbin-Macnab et al., 2016). In most cases, the literature has also indicated that, due to extended family living arrangements, grandparents may become involved in daily caregiving routines from the time of their grandchild's birth (Schatz et al., 2015). As a result of these cultural and traditional expectations, grandparents may voluntarily step into the parent role or they may at times feel forced into taking on this responsibility, even if unwillingly so (Njororai & Njororai, 2013). The literature has also indicated that family conflicts may contribute to the grandparents' levels of stress due to disagreements with their adult child over the practices of raising the grandchild or due to social issues of the adult child (Gordon, 2018).

The accumulated effects of these caregiving challenges have been indicated to become sources of stress (Rubin, 2013) and, at times, sources of distress for parenting grandparents (Doley, Bell, Watt, & Simpson, 2015). These sources of stress may negatively influence the well-being of the grandparents, where they may experience symptoms of anxiety and depression as a result of stress (Dolbin-Macnab et al., 2016; Doley et al., 2015; Hayslip, Blumenthal, & Garner, 2015). Social support has been indicated to be a possible mitigating factor for stress on the well-being of parenting grandparents (Kresak & Gallagher, 2014).

Younger parenting grandparents may experience higher levels of depression and poorer mental health than older parenting grandparents due to the possibly greater levels of

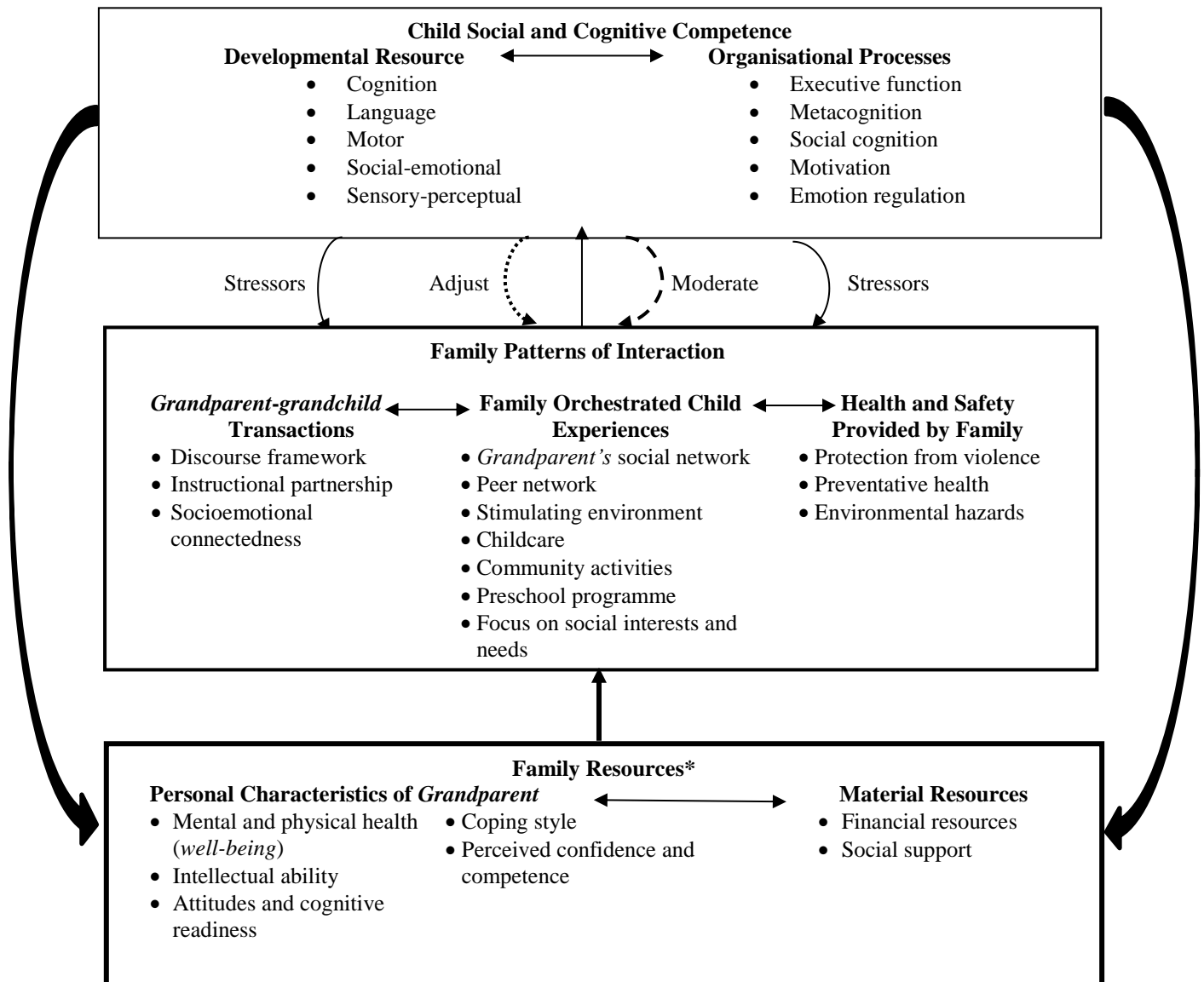
parenting responsibilities they have (Whitley, Kelley, & Lamis, 2016). However, together with the physical and emotional exertion, the familial conflict and the expectations of having to take on the caregiving role, this parenting responsibility can become a burden for the grandparents (Taylor et al., 2017). These various challenges are believed to influence the quality of care which the grandparent provides (Luo, LaPierre, Hughes, & Waite, 2012). Embedded within the quality of caregiving and parenting are the important grandparent-grandchild interactions which are believed to be fundamental in the grandchild's developmental outcomes (Choi et al., 2016).

### **2.3. The Developmental Systems Approach**

It has been proposed that the developmental outcomes of a child can be influenced either directly by their biological characteristics or indirectly by external factors stemming from the levels of the parent, family, community and the support and services they access (Guralnick, 2011). These direct and indirect factors can be either protective or risk factors which, in balance and in terms of their proximity, can determine the child's developmental outcomes (Corcoran & Nichols-Casebolt, 2004; Guralnick, 1999). The biological characteristics of the child have been suggested to include the child's developmental resources (required for language and cognition), their organisational processes (required for emotional regulation and executive functioning) and their patterns of behaviour (Guralnick, 2015). These biological characteristics may be strained if the child experiences interruptions in their typical developmental milestones, as in the case of a congenital disability (Guralnick, 2011). These developmental delays can affect and challenge the ways in which the child responds to their parent, therefore putting a strain on their relationship (Guralnick, 2015).

The reason for considering congenital disability compared to acquired childhood disabilities within this study is due to the indication in the literature that congenital disability may have deeper and more complex socio-economic influences on the health and developmental outcomes of the child (Pillas et al., 2014). The developmental outcomes of the child with a congenital disability are reliant on the environmental factors, such as health and safety within the home and community; congenital disabilities have therefore been indicated to involve greater health and financial burdens (Pillas et al., 2014). Furthermore, the onset of disability at the time when the child is most vulnerable at birth requires greater adaptation and adjustment for the caregiver (Benson et al., 1991), with greater psychological stress (Tak & McCubbin, 2002).

It is further suggested that the biological risks of the child, the characteristics of the parents may also influence the developmental outcomes of the child (Guralnick, 2011). Therefore, in the current study, it is posited that grandparents raising their grandchild may also have an influence on their grandchild's developmental outcomes (Guralnick, 2013). One of the models in early childhood intervention (ECI) which considers the influences of the parent on the child's developmental outcomes is the Developmental Systems Approach (DSA) by Guralnick (2011). The model has been further demonstrated by Samuels (2013) to be a suitable framework in the context of grandparents as co-parents. The DSA (Guralnick, 2011) has undergone refinement since its development in 1998. In its most recent version (Figure 2.1), the DSA (with a proposed adaptation to parenting grandparents) provides a top-down approach to the framework, beginning with the child's social and cognitive competence, followed by the component of family patterns of interaction, and ending with the component of family resources (Guralnick, 2011).



**Figure 2.1: A proposed adaptation of the Developmental Systems Approach as applied to a parenting grandparent (from “Developmental science and preventive interventions for children at environmental risk” by Guralnick, 2013:19. Adaptations are indicated in italics.)**

From the DSA (Guralnick, 2011), the central component of the pathways to the child’s social and cognitive competence is the component of family patterns of interaction. This is comprised of the domains of parent-child transactions, the family-orchestrated child experiences and the health and safety provided by the family (Guralnick, 2011). Guralnick (2011) suggests that these three proximal domains are crucial for positive child developmental outcomes specific to the development of the social and cognitive competencies of the child. In Figure 2.1, the dotted arrow (↔) between the child’s social and cognitive competence and the family patterns of interaction represents the moderation and influence of the child’s characteristics on the family patterns of interaction (Guralnick, 2013).

The dashed arrow (↘) represents the successful adjustments which the grandparent makes to accommodate the child's characteristics (Guralnick, 2013). Guralnick (2011) proposes that within a setting where the environmental risks are exacerbated, there may be reduced adjustments to the child's disability. As a result, these may become forms of stress which influence the family resources (represented by the large arrows flowing from outside of the levels of the child to the family resources). In time, it is possible that the stressors influencing the family resources from the child's disability may in turn affect the family patterns of interaction, represented in Figure 2.1 by the bold arrow (↑) from the family resources to the family patterns of interaction (Guralnick, 2013).

The DSA further proposes that these family patterns of interaction can be directly influenced by the component of family resources, which contains the personal characteristics of the parent (in this case the grandparent) and the domain of material resources (Guralnick, 2011). The personal characteristics of the grandparent can consist of their mental and physical health, their intellectual ability, their cultural and traditional values which influence their child-rearing attitudes, their coping styles, their perceived competence and their confidence as a parent of the child (Guralnick, 2011). Furthermore, the DSA (Guralnick, 2011) suggests that the presence of material resources, in the form of financial support and social support, may reduce the possible adverse effects of the personal characteristics of the grandparent with indirect influence on the family patterns of interaction and child developmental outcomes. The current study uses the DSA as a framework as it acknowledges that the personal characteristics of the grandparent may have an influence on the child's developmental outcomes.

In the context of grandparents raising their grandchild with a disability, it has been suggested by the model that the mental and physical health of the grandparent relates to their well-being (Guralnick, 2011). As a personal characteristic, the well-being (mental and physical health) of the grandparent in the DSA (Guralnick, 2011) can be influenced by stressors which may emerge from internal processes and external processes. For example, the internal processes may be from poor parent well-being, and external processes may be from the strained financial resources or the absence of reliable social support (Guralnick, 2001). Social support within the DSA is considered to be a resource which stems from family, friends and community networks (Guralnick, 2011).

Considering that the grandchild is the focus of the care provided by the grandparent, the quality of care is essential to optimise the child's developmental outcomes. However, according to the DSA, the quality of care may be reliant on the types of family patterns of interaction, which can be influenced by the levels of well-being of the grandparent. In the general parenting literature, it has been suggested that the poor well-being of the parent may result in poor patterns of interaction, with poor quality orchestrated child experiences and even unsafe or an unhealthy family environment (Guralnick, 2015). In the context of parenting grandparents, it is, therefore, crucial to preserve their well-being to optimise the quality of care they are able to provide to their grandchild (Guralnick, 2015).

However, the extent of literature on parents of children with a congenital disability has indicated that the presence of stress and the presence, or lack, of social support may influence the well-being of the parent (Crnic, Neece, McIntyre, Blacher, & Baker, 2017; Jean, Mazlan, Ahmad, & Maamor, 2018; Trivette, Deal, & Dunst, 1986). There have been common indications that parents (mothers) raising children with congenital disabilities, such as autism, intellectual disability, global developmental delays, fragile X syndrome, cerebral palsy or foetal alcohol syndrome (FAS), tend to report high levels of stress (Lee, 2013; Vanegas & Abdelrahim, 2016). Stressors may relate to the difficulty in finding the suitable treatment avenue for their child, the exclusion of the child from the formal education system, family responsibilities and strained financial situations (Vanegas & Abdelrahim, 2016). The result of the stress in parents may result in high levels of depressive symptoms, poor mental health related to psychiatric functioning and poor physical well-being as a result of maternal stress as a parent of a child with a congenital disability (Lee, 2013).

Parents may also experience varied positive and negative emotional well-being (Lee, 2013). Positive emotions may be associated with happiness, self-esteem, self-efficacy and personal growth, while negative feelings can manifest in the form of feelings of anxiety, anger as well as pessimism (Lee, 2013; Vanegas & Abdelrahim, 2016). These emotions have been found to vary according to the congenital disability (fragile X syndrome, autism, Down syndrome) of the child and the age of the child (toddler compared to adolescent) (Lee, 2013). It has been suggested that the high levels of anxiety and depressive symptoms experienced by parents may be dependent on the severity of the child's disability and on the child's challenging disability-related behaviour (Lee, 2013; Vanegas & Abdelrahim, 2016). However, it has also been indicated that the influences of stress may vary according to the availability and

provision of social support to the parent as per cultural roles (Vanegas & Abdelrahim, 2016). Parents who have more extensive social networks and increased family support have been indicated to have low levels of depressive symptoms and better psychological well-being (Lee, 2013). On the other hand, literature on parenting has also indicated that high levels of unhelpful or negative support to the parent may lead to an increase in depressive symptoms (Lee, 2013). These varied influences of social support on the well-being of the parent (Lee, 2013) indicate that there may be certain contextual factors which determine whether the social support is perceived to be a resource as per the DSA (Guralnick, 2011) or as a source of stress to a parent. While the influences of social support and parenting stress (and caregiving stress) on the well-being have been indicated for parents raising a child with a congenital disability, research has yet to establish whether these influences are similar or different for parenting grandparents raising their grandchild with a congenital disability. It is further inferred that there may be characteristic differences (such as age) between parents and grandparents, which can influence how caregiving stress and social support influence the well-being differently in grandparents raising a grandchild with a congenital disability.

## **2.4. Grandparents Raising Their Grandchild with a Congenital Disability**

The findings in the literature on the DSA presented above and on parents raising a child with a congenital disability provide a platform for making possible assumptions about grandparents raising their grandchild with a congenital disability as is proposed in the adapted DSA in Figure 2.1. However, as highlighted by Dolbin-MacNab and Yancura (2017), parenting grandparents are unique among their own population, which makes generalising the literature from parents to parenting grandparents problematic. Therefore, it is critical to identify the extent of literature specific to grandparents of grandchildren with a disability. To fully understand the literature related to grandparents raising their grandchild with a congenital disability, a systematic search was conducted. The aim of the search was to identify literature on grandparents raising their grandchild with a congenital disability, with a specific focus on the three constructs of stress, well-being and social support, which were discussed as important in the DSA.

### **2.4.1. Systematic search**

A systematic search was used to identify and describe the literature focusing on grandparents raising their grandchild with a disability. The search terms used were *grandparent raising*



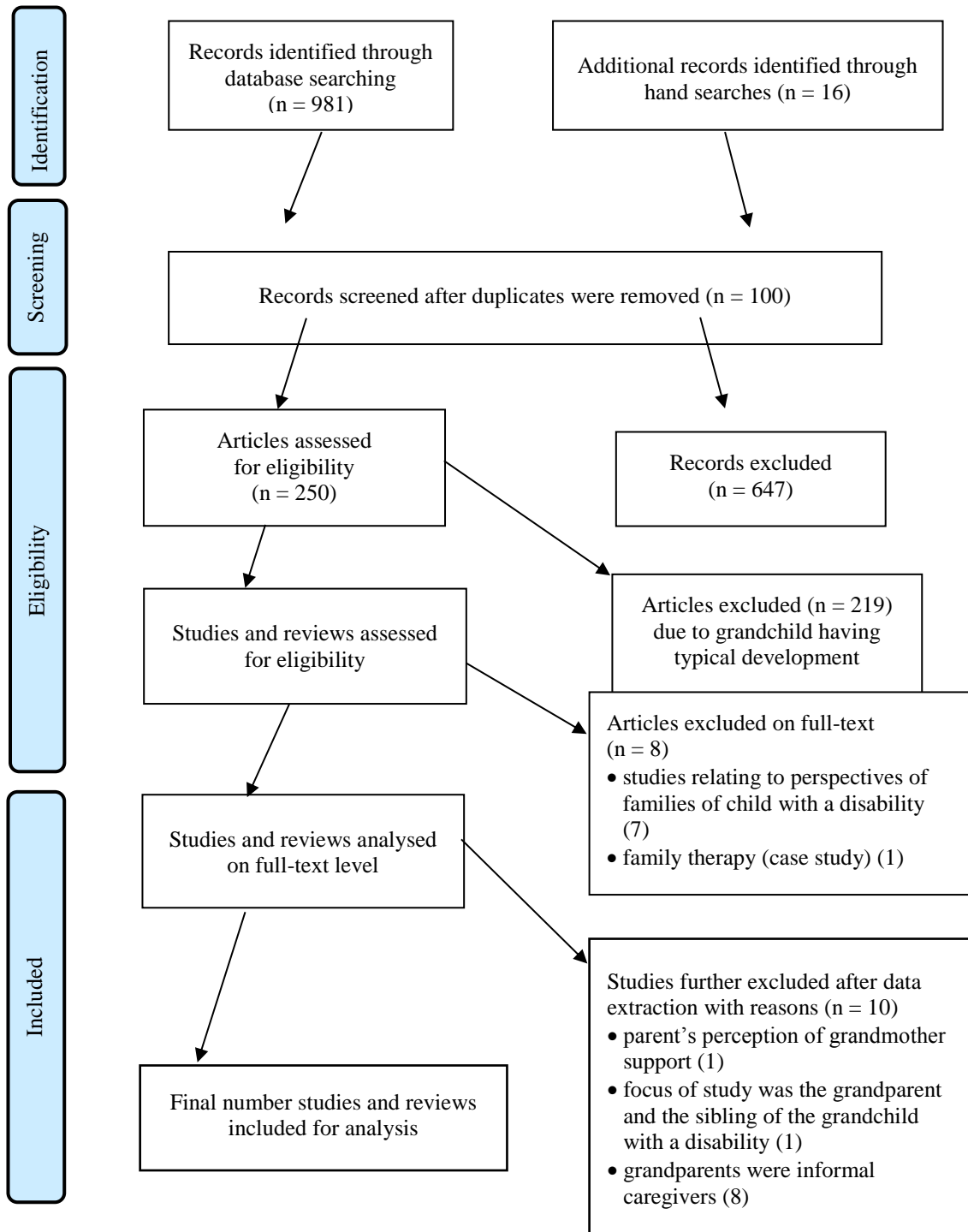
*grandchild* OR *grandparent parenting* OR *custodial grandparent* OR *co-parent\** AND *grandchild with disab\**. A total of six databases were searched, namely *Academic Search Complete*, *Africa-Wide Information*, *Family & Society Studies Worldwide*, *PsychINFO*, *Social Work Abstracts* and *TOC Premier*. Limiters were set to retrieve peer-reviewed journal articles in English from 2004 to 2019. Additional hand searches were done using ancestry searches as well as forward citations of included articles. For the hand-searched literature, only literature which was published between 2016 and 2019 was included to narrow down the results to the most recent and relevant information for the review on grandparents raising their grandchildren with disabilities. Table 2.1 outlines the inclusion criteria for the literature.

**Table 2.1: The Inclusion and Exclusion Criteria for Studies**

Inclusion criteria	Exclusion criteria	Rationale
	<b>Grandparent population</b>	
The grandparent is involved in raising the grandchild, where they are either a co-parent or a sole parent.	The grandparent is an informal caregiver	Keeping the search broad to all grandparents involved in raising their grandchild ensured that the search would be sensitive to also bring out literature pertaining to grandparents raising a grandchild with a disability.
The grandparent takes part in the daily caregiving and parenting process of raising the grandchild.	Biological parent perspectives	
	Family perspectives	
	Siblings perspectives	
	<b>Grandchild population</b>	
The grandchild has a congenital disability	The grandchild has a medical diagnosis (cancer and HIV and epilepsy)	The literature shows that the issues are different in the population of parents of children with a medical illness as opposed to disability, due to the condition of the child (Kim & Chung, 2016).
The grandchild is between the ages of 0 to 17 years 11 months.	The grandchild is 18 years or a young adult	
		The chosen age range pertained to the child developmental ages (0 to 18 years).

The search process is illustrated in the PRISMA flow diagram in Figure 2.2. A total of 981 records were retrieved. Thereafter, 100 duplicates were removed, resulting in 881 studies. A further 14 records were found in hand searches, resulting in 10 studies and 6 reviews on grandparents of children with a disability. Therefore, 897 articles were screened on title level from which 647 were excluded. The remaining 250 studies and reviews were analysed for further review on the abstract and full-text level. Of these, 219 articles were excluded as they pertained to parenting grandparents in general, leaving 31 articles to be analysed on a full-text level. Eight studies were further excluded as they pertained to families with no specific mention of grandparents in their study population. This resulted in 23 articles for data extraction. Ten studies were further excluded for reasons provided in Figure 2.3. Therefore, a

total of 13 articles (7 studies and 6 reviews) were analysed. The 7 studies are summarised below in Table 2.2 in terms of the authors, year of publication, the title of the study, the aim of the study, the population studied, the main findings, the study design and procedures, the measures used and the constructs measured. The data from the 6 reviews are integrated within the following sections as valuable information related to the general trend of literature.



**Figure 2.2: PRISMA Flow Diagram of Searches**

(Adapted from Moher, Liberati, Tetzlaff, & Altman, 2009 & The PRISMA Group, 2009)

The information from each of the seven studies is described in Table 2.2 in relation to the study author(s), the year and title of publication, the study country and population, the aim, design and procedure constructs measured, and the interpretation of the study's main findings.

Table 2.2 Summary of Studies on Grandparents Raising Grandchildren with a Disability

Author(s), year and title of publication	Country and population	Study aim, design and procedure	Constructs measured	Interpretation of the study's main findings
Gardner, Scherman, Efthimiadis and Shulzt (2004)  <i>Panamanian grandmothers' family relationships and adjustment to having a grandchild with a disability</i>	<b>Panama:</b>  <b>Co-parenting</b> grandmothers (n = 30 with education below grade 6), of children (aged 2–21 years) with a disability (physical and intellectual disability)	To explore the family relationships, grandmother role adjustments and the construct of social support of grandmothers raising their grandchild with a disability  Qualitative: Semi-structured interview	1) family relationships 2) role adjustment within the family 3) sources of support (emotional) 4) helpfulness of support of network 5) types of support provided by the network	1) Family relationships: families may split or come together over a disability. Disability may be a source of stress with <i>family conflict</i> due to adjustment to the child's disability. Grandmother's stress and worries related to possible exclusion of their grandchild from the community, a poor future in terms of health and welfare and regarding who will look out for the child in the future when they are not alive anymore. 2) Role adjustment of grandmother relates to providing direct care to the grandchild with their perceived role as co-parent assisting with caregiving, home chores, helping the grandchild with school work, raising funds for the grandchild's disability, performing rituals to provide emotional support and advice to the mother. Grandmothers have a positive relationship with their grandchild with love, affection acceptance and patience (can infer positive emotional well-being due to close attachment with the grandchild). 3) Grandparent's source of emotional support from: parent of the child, spouse, another grandparent, own parent (great grandmother), other relatives or no one (can infer that family ties are significant but relied upon for mental health support because of possible shortage of mental health services; may allude to the importance of informal support and possible effect if there is a lack thereof). 4) Helpfulness of sources of support when raising grandchild: most helpful supports were the parent of the child, other relatives, their spouse, and special services. 5) Type of support provided by the network: caregiving (instrumental), emotional support, financial support, special services.
McCallion, Janicki and Kolomer (2004)  <i>Controlled evaluation of</i>	<b>America:</b>  <b>Sole-parenting</b> grandparents (n = 97 with an education above	To test the effect of a support group on the well-being of grandparents raising	1) caregiving stress 2) well-being related to depression, sense of mastery and	1) Caregiving stress: related to caretaking role, aging, financial strain, work, housing, caregiving demands, lifelong characteristic needs of disability, conflicts in accessing services, lack of respite meant the grandparent could not attend the meeting (can be inferred that caregiving does not allow them time to seek formal support services – lack of respite), fears of being perceived as being unable to raise their grandchild.

Author(s), year and title of publication	Country and population	Study aim, design and procedure	Constructs measured	Interpretation of the study's main findings
<i>support groups for grandparent caregivers of children with developmental disabilities and delays</i>	high school), of children (mean age of 11 years) with a disability (intellectual disabilities, ADHD, developmental delay)	their grandchild with a disability  Quantitative: Group design intervention provided two groups of grandparents with a time delay between both groups.	parenting empowerment  3) helpfulness of social support	2) Well-being following support group: declines of symptoms of depression, with an increased sense of empowerment and caregiving mastery in the grandparents (can indicate the positive effects of social support in the form of support groups).  3) Helpfulness of social support (support group): provided with information about how to access services and addressed their unique needs to understand grandchild's disability. Resulted in better levels of mastery and parenting empowerment. The grandparent had positive appraisals by knowing that they are not alone and have similar concerns. The support groups were specific to the grandparents. Provided them with a greater sense of ownership. The relevance of the support group seemed to encourage attendance. Because some grandparents did not have respite care to attend the group, support groups alone may not be sufficient to bring down the levels of depression (can indicate the need to also consider personal and informal ties and the need for respite care).
Penn, Watermeyer, MacDonald and Moabelo (2010)  <i>Grandmothers as gems of genetic wisdom: Exploring South African traditional beliefs about the causes of childhood genetic disorders</i>	<b>South Africa:</b>  <b>Co-parenting</b> grandmothers (n = 15) of children with and without disabilities	To explore traditional roles in child-rearing and beliefs of South African grandmothers regarding the causes and prevention of common childhood genetic disorders  Qualitative: focus groups	1) roles related to childcare  2) cultural perspectives of disability  3) influences of cultural perspectives on disabilities	1) The roles of the co-parenting grandmothers related to childcare were reported as: cooking, fetching water, checking whether children have adequately eaten, teaching life skills, providing advice and managing health issues in a traditional manner. The grandparents also saw their role in the family as decision makers, reproductive mentors to their children as industrious and resourceful.  2) Cultural perspective of disability for causes of genetic disorders was due to: the lifestyle choices, the behaviours of the mother while pregnant, social causes such as domestic abuse, familial causes such as consanguinity, religious causes such as not following rituals, and genetic causes related to the older age of mother.  3) Prevention strategies related to abortion/infanticide, traditional medicines, delaying sexual maturity, cleansing rituals and abstinence.
Gallagher, Kresak and Rhodes (2010)	<b>America:</b>  <b>Sole-parenting</b> grandmothers	To determine the concerns and needs of custodial grandmothers raising	1) caregiving and parenting stress	1) Caregiving and parenting stress: the increase in the amount of care required by the child, child supervision needed at all times, the challenges of understanding the special education process, having to fill in the parenting roles, having to raise more than one child. High

Author(s), year and title of publication	Country and population	Study aim, design and procedure	Constructs measured	Interpretation of the study's main findings
<i>Perceived needs of grandmothers of children with disabilities</i>	(n = 20) children (aged 3–12 years) with disabilities (autism, cerebral palsy, foetal alcohol syndrome, intellectual disabilities, shaken baby syndrome, multiple disabilities and other)	grandchildren with disabilities  Qualitative: semi-structured interview	2) needs of grandmothers  2) needs for support  3) effect of met needs on satisfaction on the emotional well-being  4) effect of needs met on grandparent-grandchild relationship	behaviour and high needs of the grandchild can also influence the grandparent's well-being being tired and "worn out".  2) Needs of grandmothers: did not explain "perceived" support theoretically, used the word "perceived" only in the title. The grandmothers required strategies on how to manage the behaviours of their grandchild (such as aggression or runner issues). They needed help with teaching the child how to talk or sit and home intervention. Resources for their grandchild were needed, for instance computer/car seat/tutoring, as well as more information about the grandchild's special needs, for instance information from other professionals. Another requirement was respite care to take a break as well knowing the grandchild's prognosis and therapy progress. Access to better funding, transportation, adaptations in the home, medication for child were also reported to be lacking.  3) Effect of met needs: adequate emotional and instrumental support can reduce the effects of stress.  4) Effect of met needs on the relationship of grandmother and grandchild relationship: the grandmothers reported that they knew what to do and how to manage their grandchild with improvements in the grandchild's behaviour (mastery).
Kresak, Gallagher and Kelley (2014)  <i>Grandmothers raising grandchildren with disabilities: Sources of support and family quality of life</i>	<b>America:</b>  <b>Sole-parenting</b> grandmothers (n = 50 with majority high school education) of children (aged 2–21 years) without and another group of grandmother of children with a disability (ADHD,	To identify the mediating effects of social support on the family quality of life of grandmothers raising a grandchild with and without a disability  Quantitative: survey	1) sources of social support  2) satisfaction of grandmothers with their quality of life (as a variable of well-being)  3) mediating factors of family supports	1) Sources of support: same for both groups but grandmothers of children with a disability had lower levels of informal support than grandparents of children without a disability. Raising a grandchild with a disability may be more socially isolating due to grandchild's disability.  2) Quality of life (QoL): grandmothers of children without a disability had higher levels of QoL than grandmothers of children with a disability. This may be due to the increased levels of stress or poorer well-being amidst disability of the grandchild. The grandmothers of children with disabilities had lower levels of satisfaction of life (may imply lower well-being).  3) Indicates social support and family resources can increase the family QoL and positive family and child outcomes.

Author(s), year and title of publication	Country and population	Study aim, design and procedure	Constructs measured	Interpretation of the study's main findings
	foetal alcohol syndrome, behaviour disorder, cerebral palsy, fragile X syndrome and learning disability)		on quality of life of grandmothers  4) helpfulness of social support	<p>3) Mediating factor of social support: there was a significant relationship between the disability of the grandchild and the sources of support and satisfaction of QoL. May imply that less contact with family and friends can be due to grandchild's disability being prioritised, may explain lower satisfaction with family interactions. There was also an indication of lower levels of material/physical well-being of grandparents of children with a disability than those without a disability. This may be as a result of higher financial expenses due to grandchild's disability, which may affect the grandparent's physical health.</p> <p>4) Helpfulness of social support: informal support was also seen to be less helpful. May imply social isolation due to greater caregiving demands with family and friends not able to or not willing to provide help to the grandparent because of challenging behaviours. There was a significant correlation between total formal support and satisfaction of QoL for grandmothers raising grandchildren with a disability, where support from family and friends can increase the emotional well-being, thereby increasing the satisfaction of family quality of life. Formal supports were seen as unhelpful or not accessed or sought by the grandparents, due to difficulty accessing formal services. Alternatively, formal services may not be equipped to meet the unique needs of the grandparents, the grandparent feels they can manage the problems themselves or they may not be motivated to seek assistance or do not have the time. The helpfulness of informal or formal support was not significant for grandparents of children with a disability.</p>
Brown, Churchill, Laghaie, Ali, Fareed and Immergluck (2017)  <i>Grandparents raising grandchildren with disabilities: Assessing health status, home</i>	<b>America:</b>  <b>Sole-parenting</b> grandparents (n = 46 education level not mentioned) of children (age not provided) without and with a disability (ADD, ADHD, asthma,	To investigate the effect of the programme on the perception of grandparent's quality of life specific to their perceived health and of the home environment of grandparents raising a	1) caregiving stress  2) quality of life (well-being)  3) effect of social support (groups) and case management	<p>1) Caregiving stress: the perception of stress varies among parenting grandparents according to the levels of stress, the number of stressors and the outlook of and the support accessed by each grandparent. Sources of stress may be due to the home adjustments and financial adjustments which can be emotionally stressful. Funds may be limited with increased financial burden because of the re-allocation of funds to the child's disability, medical needs or transportation needs.</p> <p>2) Physical health status (well-being): 44% of the grandparents reported improved health since having joined the intervention. Not all grandparents in the study (only 32%) reported stress. Grandparents felt energised by their caregiving role with a possible sense of purpose, which means that they had positive emotions related to caregiving. Others felt tired, burdened and isolated due to their parenting responsibility. Grandparents may need to manage their</p>

Author(s), year and title of publication	Country and population	Study aim, design and procedure	Constructs measured	Interpretation of the study's main findings
<i>environment and impact of a family support case management model</i>	behavioural disorders, autism, learning disabilities, and developmental disorders)	grandchild with a disability  Quantitative:  survey		grandchild's health together with their own health well-being (presence of chronic diseases such as hypertension, diabetes, heart disease and arthritis) which require more medical attention and medication and may result in limited mobility. Grandparents may neglect their own health and prioritise their child's health instead.  3) Effect of social support: there was an overall improvement in the grandparents' perceived health well-being. Perceived health did not change in relation to the length of time of intervention and the number of resources. However, the quality of the relationship between the case manager and the grandparent indicated improved levels of perceived health and home environment. It is possible that the improved perceptions of health are related to the needs of the grandparent being met through appropriate referral and due to the needs met in the home environment. It is also possible that the grandparent's access to a grandparent support group also contributed to improved perceived health.
Hillman and Anderson (2019)  <i>It's a battle and a blessing: The experience and needs of custodial grandparents of children with Autism Spectrum Disorder</i>	<b>America:</b>  <b>Sole-parenting</b> grandparents (n = 117 with majority having a college or associate degree) of children (aged 2–44) with ASD	To explore the sources of stress and joy of grandparents  Qualitative:  The grandparents completed a two-part survey online containing open-ended questions	1) caregiving stress related  2) coping strategies for emotional well-being	1) Stress: <i>ASD behaviour</i> (running away/tantrums/communication difficulties/social skills/toilet training/fussy eating); <i>insufficient individualised services for their grandchild</i> (finding ways for communication / finding appropriate residential care / not feeling that services understand the child / needing better practical advice on how to manage the child); <i>finances strains</i> related to the high cost of ASD treatments, daily necessities and other (respite care, diapers, therapy, communication aids, regular appointments), need to seek employment to afford the necessities; <i>24/7 demands</i> (cannot leave home / constant supervision required / physical exhaustion / social isolation / feelings of not being understood by the formal services / no access to reliable respite care / feeling of hopelessness for theirs and grandchild's situation); <i>family conflicts</i> (conflict with the parent of the grandchild who does not understand the child's need for routine, custody fights and not respecting visitation rights); <i>fear of the future</i> (who will take care of their grandchild should they die?).  2) Grandparents expressed their coping strategies were around:  - celebrating the small achievements of their grandchild and experiencing positive emotions  - having unconditional love for their grandchild and valuing their relationship



<b>Author(s), year and title of publication</b>	<b>Country and population</b>	<b>Study aim, design and procedure</b>	<b>Constructs measured</b>	<b>Interpretation of the study's main findings</b>
				<p>- relying on their spirituality and faith by being religious and having moral beliefs to sustain their emotional well-being</p> <p>- focusing on the positives by being grateful to have a grandchild who may be affectionate, being grateful for their situation and not anything worse.</p> <p>The grandparents further indicate wisdom where they expressed having experienced personal growth by being more patient or learning valuable life lessons from raising their grandchild. The value of social support, having connections with friends, family, neighbours and professionals.</p>

#### 2.4.1.1 *Grandparent populations, countries of study, sample sizes and study designs*

The systematic literature search (Table 2.2) on grandparents raising a grandchild with a disability shows that these grandparents may be sole parents (Gallagher, Kresak, & Rhodes, 2010; Hillman & Anderson, 2019; Kresak et al., 2014; McCallion et al., 2004) or co-parents (Gardner et al., 2004; Penn et al., 2010). The review identified a higher number of studies carried out in America (five studies), one in Panama and one in South Africa. It is concerning that there has not been a greater expanse of research globally on grandparents raising their grandchild with a disability. This paucity of global research on this specific population is present despite the global rise in awareness of the impact of childhood disability in families (Collins et al., 2017), the acknowledgement of the need for early intervention (Guralnick, 2017) and the recognition of the increase in grandparent caregivers (Buchanan & Rotkirch, 2018). The small number of articles identified in this review indicates that there is a need for more knowledge from other countries, and specifically South Africa as only one study (Penn et al., 2010) was identified.

The six reviewed studies covered a comprehensive range of diagnosed congenital disabilities, namely attention deficit and hyperactivity disorder (ADHD), Foetal Alcohol Syndrome, behaviour disorders, cerebral palsy, autism, fragile X syndrome, learning disability and intellectual disability. The population sample sizes of the studies in the review were staggered, where some studies had small sample sizes ranging from between (N = 15) (Penn et al., 2010) and (N = 20) (Gallagher et al., 2010) to larger sample sizes of (N = 97) (McCallion et al., 2004) and (N = 117) (Hillman & Anderson, 2019). The studies used qualitative methods via focus groups and individual interviews (Gallagher et al., 2010; Gardner et al., 2004; Hillman & Anderson, 2019; Penn et al., 2010), and quantitative methods by using a survey designs (Brown et al., 2017; Kresak, Gallagher, & Kelley, 2014; McCallion et al., 2004).

The general literature on the world literacy levels shows that, globally, there are indications of the prevalence of low levels of literacy within the elderly population (Roser & Ortiz-Ospina, 2018). On closer inspection of studies which used quantitative survey designs, self-reporting questionnaires were used (Brown et al., 2017; Kresak et al., 2014; McCallion et al., 2004). However, two studies (Brown et al., 2017; McCallion et al., 2004) did not mention the education level of the grandparents and only one study mentioned that the grandparents had

schooling attainment below high school to graduate degrees (Kresak et al., 2014). There was no mention in any of the studies (Brown et al., 2017; Kresak et al., 2014; McCallion et al., 2004) of whether adaptations were made to the questionnaires to accommodate for possible low literacy levels of the grandparents or whether grandparents with low levels of literacy were decisively excluded from the study sample due to the questionnaire format which was being used. It can thus be inferred that the studies may not have made accommodations to also include the perspectives and views of grandparents of low literacy.

The seven studies identified in the systematic search (Brown et al., 2017; Gallagher et al., 2010; Gardner et al., 2004; Hillman & Anderson, 2019; Kresak et al., 2014; McCallion et al., 2004; Penn et al., 2010) provide crucial information on grandparents raising their grandchild with a congenital disability. This information is integrated below to unpack the three main constructs of stress, well-being and social support of grandparents raising their grandchild with a congenital disability.

## **2.5. Stress When Raising a Grandchild with a Congenital Disability**

Stress in the context of grandparents raising their grandchild with a disability has been identified as complex in nature and reliant on various factors, namely personal, experiential, emotional and practical factors, which can determine how much stress grandparents face (Brown et al., 2017). There is also a temporal aspect of stress which needs to be considered in the context of stress; that is, if chronic, there is a persistent quality to the stressors (Thrasher, Clay, Chandra, & Stewart, 2012). The daily and intensive nature of raising a child with a disability has been indicated to result in accumulations of these stressors (Thrasher et al., 2012). The accumulation of these stressors can have consequent mental and physical effects on the well-being of the person raising the child (Thrasher et al., 2012).

Theories such as the social exchange theory, the role strain theory, the ecological system theory, the self-efficacy theory and the symbolic interaction theory have been found to be applicable to the context of parenting grandparents (Pandialagappan & Ibrahim, 2018). The review of the six studies has shown that studies on grandparents raising their grandchild with a disability have not made reference to these various stress processes models, possibly due to the complexities related to the grandchild's disability. In the absence of these models in the included studies, the current review therefore considers the studies obtained in the systematic search from the perspective of the proposed grandparent stress processes (Pandialagappan &

Ibrahim, 2018) in order to speculate on what factors may contribute to the stress of these specific grandparents.

### **2.5.1. Factors of stress for grandparents.**

The social exchange theory suggests that stress may surface due to the disproportion between the heightened demands of raising a grandchild, which surpass the grandparent's resources available to fulfil these expectations (Pandialagappan & Ibrahim, 2018). For example, when grandparents age, they have reduced levels of energy which may become disproportionate to the increased energy and time they require when raising their grandchild with a disability (e.g., grandchild's poor mobility, higher levels of activity or disability-related behaviour problems) (Gordon, 2018; Kresak & Gallagher, 2014). The complex family structures and the grandchild's disability-related challenging behaviours can further be sources of stress to the grandparent (Gordon, 2018).

The role strain theory suggests that parenting grandparents may experience stress due to the various roles they are expected to fulfil, where their traditional grandparent roles may be blurred by their parenting responsibility (Pandialagappan & Ibrahim, 2018). Consequently, parenting grandparents have been found to experience accumulated stressors which can lead to physical exhaustion, and reduced health and emotional well-being (Gallagher et al., 2010; Hillman & Anderson, 2019). Within the family system, stress may arise due to the conflicts with their adult child or other family members because of the blurring of the parenting and grandparenting roles which results from the adjustment to the grandchild's disability (Gardner et al., 2004; Yang, Artman-Meeker, & Roberts, 2018). For example, as identified in Hillman and Anderson (2019), sole-parenting grandparents have expressed challenges when the biological parent of the grandchild is unwilling to accommodate their special needs. Conflict has also been identified over how to manage the grandchild's disability-related behaviours, or what course of intervention to be followed for the grandchild (Hillman & Anderson, 2019; Yang et al., 2018). Any resistance from either party may be counterproductive in ensuring a harmonious home environment to raise the grandchild, where the parenting styles, parenting attitudes and parenting-child interactions may be jeopardised (Crnic et al., 2017).

The stress that grandparents experience when raising their grandchild has also been viewed as an outcome of the presence and quality of the resources from the social environment which surrounds the grandparent, contained within the ecological system theory (Pandialagappan & Ibrahim, 2018). Grandparents parenting a grandchild with a congenital disability have been identified to experience financial strains (Brown et al., 2017; Hillman & Anderson, 2019). The presence of a child's disability in a family may absorb the majority of finances available within the household due to the special needs of the child (Brown et al., 2017; Collins et al., 2017). For example, Brown et al. (2017) found that the grandparents in their study did not have enough household income to cover the costs of tailoring the home to accommodate their grandchild's disability. Other daily necessities may also include diapers and special dietary requirements or assistive devices and extra costs towards transport for frequent medical and rehabilitative services to hospitals and community clinics for the child (Hillman & Anderson, 2019). The re-allocation of funds within the household may therefore increase the social vulnerability of the grandparent and the family at large, which could affect the way in which the grandparent effectively raises their grandchild (Hanass-Hancock & Casale, 2014). In a context with vast inequalities such as South Africa, where resources may be few, it is possible that the grandparent may experience stress in coping with their caregiving role (Hanass-Hancock & Casale, 2014). It is possible to imply that this social vulnerability may be intensified in the South African context where there are high levels of poverty (Njororai & Njororai, 2013).

The lack of opportunity to seek employment due to full-time childcare (Hillman & Anderson, 2019) and the poor unemployment levels in South Africa (Schatz et al., 2015) may be a further source of stress for the grandparents. Grandparents may stress about having to rely on other persons or family members to financially support them with monthly expenses (Brown et al., 2017). In South Africa, the social grants which are available as support to the low-income families include: the child support grant of R420 (\$30) per month for children under 14 years of age; the foster child grant of R1000 (\$71) per month, which is provided only after a court order that indicates that the grandparent is the foster carer of the grandchild (Hall & Wright, 2010); the care dependency grant of R1700 (\$113) per month for when the child has a permanent and severe disability; and an old age pension of R1780 (\$127) per month if the grandparent is above the age of 60 years (Schatz et al., 2015). However, parenting grandparents who take on the parenting role before the age of 60 years may not have legal access to an old age pension fund (Ardington et al., 2010; Schatz et al., 2015).

While these various financial aids by the government are highly valued by parenting grandparents (Schatz et al., 2015), these grants remain insufficient in light of the various disability-related needs of the grandchild. The importance of highlighting these various stressors due to the financial challenges of the grandparents relates to the fact that these challenges contribute to additional undue strain on the well-being of the grandparents (Patel, Hochfeld, & Chiba, 2018).

As identified in the literature (Brown et al., 2017; Hillman & Anderson, 2019; Kresak et al., 2014), most parenting grandparents experience stress related to the legal systems and the processes which they need to follow to be legally recognised as the parent of their grandchild, so that they can receive some form of legal financial support. The grandparents may experience stress in completing the legal documents if they have low literacy levels (Schatz et al., 2015), or may find the proceedings around the obtaining of custody of their grandchild as being stressful (Hillman & Anderson, 2019), overwhelming, time-consuming and expensive logistically for grandparents (Dolbin-MacNab & Yancura, 2017). Moreover, the untimely death or sudden disappearance of the parent of the child may be a further barrier to the completion of the legal procedures for gaining full custodial care of their grandchild (Gordon, 2018).

Parenting grandparents may have highlighted the feeling of heightened stress linked to their perceived reduced self-efficacy, which is linked to the self-efficacy theory (Pandialagappan & Ibrahim, 2018). Self-efficacy involves the grandparent's perception of their capability to accomplish the parenting role and of raising their grandchild amidst unpredictable, confusing and unknown situations (Pandialagappan & Ibrahim, 2018) as in the case of their grandchild's disability (Steffen, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002). For example, grandparents have expressed heightened levels of stress in light of their grandchild's disability-related behaviours (such as tantrums, meltdowns or aggression towards the grandparent), as in the case of autism (Hillman & Anderson, 2019), FAS or ADHD (Gordon, 2018). The majority of these disability-related behaviours may relate to the grandchild's difficulty in communicating, poor sleep, moodiness, sensory processing disorders, learning difficulties or high impulsivity (Gallagher et al., 2010; Gordon, 2018; Hillman & Anderson, 2019). The social environment has been indicated to have an important role in sustaining and upholding the grandparent's self-efficacy so that the grandparent is able to cope with the caregiving demands of their grandchild (Pandialagappan & Ibrahim, 2018).

For example, grandparents in Hillman and Anderson's (2019) study experienced stress due to the constant and daily caregiving demands which rendered them exhausted and socially isolated because they did not have suitable respite and also felt misunderstood by the support services. Grandparents have also expressed the lack of formal specialised interventions for their grandchild in terms of finding ways to, for instance, assist their grandchild to communicate or to support the grandparent in managing their grandchild's behaviours (Gallagher et al., 2010; Hillman & Anderson, 2019; McCallion et al., 2004). As a result, grandparents have been found to experience social isolation, reduced time for themselves due to caregiving demands, increased financial strains and increased family strains (Pandialagappan & Ibrahim, 2018; Trivette et al., 2010).

Finally, grandparents can experience stress as a result of poor self-processes in response to their parenting role, as per the symbolic interaction theory (Pandialagappan & Ibrahim, 2018). Self-processes are those factors which encourage the parenting grandparent to carry out their responsibility; for example their self-esteem, finding their purpose, qualities which make them unique – all of which may influence the grandparent's satisfaction with their role (Pandialagappan & Ibrahim, 2018). Factors which can pose a threat to the grandparent's self-processes, leading to stress, may include their emotional and physical strains, social isolation, reduced financial resources, poor physical health and negative perceptions of the grandchild's parent towards the grandparent (Pandialagappan & Ibrahim, 2018). These factors have been identified in literature on grandparents raising their grandchild with a disability and are indicated to be a source of stress for these grandparents (Brown et al., 2017; Gallagher et al., 2010; Hillman & Anderson, 2019; Kresak et al., 2014; McCallion et al., 2004).

As a result of the multi-factorial causes of stress, grandparents have been indicated to experience various influences on their well-being. These are both physically, with manifestations of physical health problems, and emotionally through symptoms of depression, anxiety, feelings of vulnerability and strained relationships (Pandialagappan & Ibrahim, 2018; Trivette et al., 2010).

## **2.6. Well-being of Grandparents Raising Their Grandchild with a Congenital Disability**

With the shift in services, from the medical model to a family-centred intervention model in Early Childhood Intervention (ECI), there has been a greater need to involve the parents and caregivers in intervention (Moore, Kennedy, McLoughlin, Gavidia-Payne, & Forster, 2010). With greater involvement, a parent or caregiver may feel empowered to take ownership of their child's intervention and to actively seek ways to fulfil their roles and responsibilities confidently (Trivette et al., 1986) while coping with the challenges of raising their child with a disability (Guralnick, 2017). However, the lifelong nature and increasing severity of disability as the child ages (Hillman & Anderson, 2019; Kim & Chung, 2016; Samuel et al., 2017) may result in diminished well-being of the parent or caregiver, such that they may be less able to perform their daily parenting and physical caregiving duties (McConnell, Savage, & Breitreuz, 2014).

Well-being can be understood as a state of equilibrium where the resources and challenges are balanced and managed (Dodge et al., 2012). The two constructs of stress and well-being represent the affective (emotional) and the physical forms which manifest in response to how life events are perceived (Bundy-Fazioli, Fruhauf, & Miller, 2013; Pruchno & McKenney, 2002). As an affective response to raising a grandchild with a disability, grandparents may view parenting momentarily as being either life fulfilling or a burdened with stress (Sands, Goldberg-Glen, & Thornton, 2005). The conflict between the positive and negative affect towards raising a child may create internal feelings of conflict for the grandparent, especially when having to balance other roles and responsibilities (Pruchno & McKenney, 2002). To accurately characterise the emotional well-being of the parenting grandparent, it is crucial to discuss and consider these positive and negative affects (Pruchno & McKenney, 2002). Typically, the positive affect towards caregiving has been linked to external factors such as the caregiving routines and activities, the grandparent's perceived significance of their role, and the quality of their relationship with the parent of the child (Pruchno & McKenney, 2002). Further external factors also include the social behaviour of their social network and the positive relationships with their significant family and social network (Pruchno & McKenney, 2002). On the other hand, parenting burden – an adverse affect – may be attributed to the internal factors, namely the grandparent's health and the threats to their



feelings of competency in situations of heightened behaviours from their grandchild (Pruchno & McKenney, 2002). There have been further indications that the negative affect may be “so powerful” (Pruchno & McKenney, 2002, p. 450) that the poor health and feelings of parenting burden may increase the negative affect of the grandparents and also decrease their feelings of positive affect (Pruchno & McKenney, 2002). However, the combination of positive and negative affect in the literature alludes to the fact that the well-being of parenting grandparents may not be exclusively positive or negative (Pruchno & McKenney, 2002). Furthermore, the positive and negative affect of parenting grandparents may also vary between co-parenting and sole-parenting grandparents.

Co-parenting grandparents raising their grandchild with a congenital disability may have the opportunity to withdraw themselves from the demands of parenting and caregiving when they are overwhelmed and have the option of the parent of the child to take over. However, co-parenting grandparents have expressed difficulty in breaking away from their parenting obligation due to the perceived family expectation that they need to help the parent of their grandchild (Kirby & Sanders, 2012). Co-parenting grandparents may, however, have space and time to go through the denial and acceptance stages of the disability of their grandchild due to lower levels of caregiving responsibility (Woodbridge et al., 2009b). Co-parenting grandparents may also have the opportunity to learn from and with the parent of the child about how to fulfil their grandchild’s special needs. However, co-parenting grandparents have been found to experience stress from conflicts with the parent of the grandchild due to differing expectations for the child, communication problems as well as differed views on parenting strategies (Kirby & Sanders, 2012).

Unlike co-parenting grandparents, sole-parenting grandparents may not have the option of withdrawing themselves from caregiving due to the lack of reliable respite (Hillman & Anderson, 2019) and the onset of their caregiving responsibility may not afford them the time to adapt and accept their grandchild with a congenital disability (Janicki et al., 2000). They may also be more prone to depression and emotional strains in having to deal with the reasons for the absence of the parent of their grandchild, especially if they have unresolved issues and trauma around, for example, the death of their adult child (Gordon, 2018). Sole-parenting grandparents have expressed feeling overwhelmed when having to launch into raising their grandchild alone with little to no preparation in how to manage the disability of their grandchild (Kresak, Gallagher, & Kelley, 2014).

### **2.6.1. Physical well-being of the parenting grandparents.**

The physical well-being of the grandparent refers to the various health-related components of well-being as an outcome of caregiving demands from the grandchild with a disability (Gardiner et al., 2018). With congenital disabilities, the physical challenges of parenting grandparents have been indicated to be challenging in terms of the daily activities, such as bathing, toileting and feeding (Hillman & Anderson, 2019).

Grandparents may experience reduced age-related abilities (Samuel et al., 2017), which increase their physical strains due to the intensifying physical caregiving demands as the grandchild with a disability grows (Gardiner et al., 2018). The physical caregiving demands may be further exacerbated depending on the severity of the grandchild's disability (Samuel et al., 2017). For example, a grandchild with severe to profound disabilities may be more difficult to move during bathing and toileting (Gardiner et al., 2018). The grandchild may also require constant supervision for their own safety within the home or the child may be heavily dependent on the grandparent for their daily needs (Hillman & Anderson, 2019; Kresak et al., 2014). These may be possible reasons why older grandparents tend to report reduced levels of health compared to younger grandparents (Luo et al., 2012; Samuel et al., 2017; Whitley, Whitley, Lamis, & Kelley, 2016). As a result of the strained physical care, the grandparent may be exhausted and may have lower levels of energy when needing to engage in quality interactions and enjoyment with their grandchild (Hillman & Anderson, 2019).

Grandparents raising their grandchild with a disability may be at a heightened risk for the development of health, such as diabetes, arthritis or heart disease (Brown et al., 2017; Gallagher et al., 2010; Kresak et al., 2014; Muliira & Musil, 2010). Although these conditions may be age-related, research has shown that the onset of chronic medical conditions may be as a result of changes in lifestyle associated with the caregiving demands (Muliira & Musil, 2010). In cases where grandparents have had chronic medical conditions prior to raising their grandchild, it has been indicated that these conditions may be aggravated due to the caregiving demands (Muliira & Musil, 2010).

The aggravation of the chronic medical conditions may also be due to the fact that grandparents may prioritise their grandchild's disability-related needs over their own medical needs (Brown et al., 2017; Muliira & Musil, 2010). Parenting grandparents often neglect their

own health by not keeping up with frequent visits to their doctor or not accessing the medications they require (Muliira & Musil, 2010). The presence of poverty and strained finances may lead to difficulty in setting aside part of their household income for their own medical check-up or to buy their own chronic medications, owing to the need to provide for their grandchild's special needs (Brown et al., 2017; Smithgall, Mason, Michels, Licalsi, & Goerge, 2007). However, research has shown that the responsibility of raising a grandchild with a disability influences not only the physical well-being of the grandparent but also their emotional well-being (Hayslip, Fruhauf, et al., 2017; Kresak et al., 2014).

### **2.6.2. Emotional well-being of the parenting grandparent**

Emotional well-being has been defined as the affective component of mental health, where positive feelings such as happiness, cognitive components relate to the satisfaction of life and optimism (Lamers et al., 2012; Schotanus-Dijkstra et al., 2017). The affective emotions relate to the internal and external behaviours in response to adverse life events (Bundy-Fazioli et al., 2013). Emotional well-being further encompasses the ways in which the individual manages their emotional actions amidst unhealthy stress or distress (Bundy-Fazioli et al., 2013). Therefore, in the context of stress from raising a grandchild with a disability, the consequent emotional and affective symptoms which surface from this responsibility are crucial. In caregiving, emotions are important in determining the quality of the relationships and interactions between the parent and the child, where the child relies on and learns about social cues and emotional expression during the family patterns of interaction (Guralnick, 2005). Research has shown that with poorer well-being, the emotional state of the grandparents may be lowered (Kresak et al., 2014). This infers that the quality of interactions may be threatened with resultant influence on the developmental outcomes of the grandchild.

From the general parenting literature, the emotional well-being of parents has been indicated to influence their parenting behaviours (Respler-Herman, Mowder, Yasik, & Shamah, 2012). Successful parenting has been indicated to be reliant on three factors, namely the presence of psychological resources available to the parent in relation to their emotional well-being, the effect of the child's characteristics on the parent and the effect of the broader contextual sources of stress and social support on the parent-child relationship (Belsky 1984 cited in Respler-Herman et al., 2012). In the context of grandparents raising their grandchild with a

congenital disability, it is possible to infer that these three key areas may also determine the parenting quality of the grandparents.

The presence of psychological resources in parenting has been indicated to influence the emotional well-being of the parent and to sustain the emotional well-being of the parent when self-efficacy stress arises (Ben Shlomo & Taubman-Ben-Ari, 2012). During situations of stress, the psychological resources enable the parent to problem-solve effectively and to be resourceful in acquiring the knowledge and skill they require to manage and care for the special needs of their child. Psychological resources include parenting skills, such as optimism and self-mastery (Ben Shlomo & Taubman-Ben-Ari, 2012), where optimism refers to the positive beliefs and hopes for one's life course (Ben Shlomo & Taubman-Ben-Ari, 2012). Self-mastery refers to the degree of control which the individual perceives to have over their life (Ben Shlomo & Taubman-Ben-Ari, 2012). Optimism relates to the positive emotions linked to feelings of happiness, satisfaction as a parent and feeling positive regarding the future for grandparents raising their grandchild with a congenital disability (Gallagher et al., 2010; Hillman & Anderson, 2019). The skills of self-mastery, on the other hand, relate to how confident and empowered the grandparent feels towards their role when raising their grandchild with a disability (Gallagher et al., 2010; McCallion et al., 2004). As previously mentioned, the concept of self-efficacy is also strongly linked to the parent's competence (Gilmore & Cuskelly, 2009) and their feeling of confidence in terms of their ability to effectively practise their parenting role.

The literature has indicated that grandparents may exhibit symptoms of poor emotional well-being through depression and anxiety (Gordon, 2018; Hillman & Anderson, 2019; McCallion et al., 2004). The causes of these symptoms have been linked to emotions such as worry, fear or sadness. For example, grandparents have expressed experiencing a fear of the future of their grandchild in terms of their possible exclusion from their community due to their disability (Gardner et al., 2004). They may also worry about not doing enough for their grandchild in terms of intervention options (Hillman & Anderson, 2019; Kresak et al., 2014; McCallion et al., 2004). Furthermore, grandparents have expressed fear for their grandchild's future should the grandparent not be alive to continue caring for their grandchild (Gallagher et al., 2010; Hillman & Anderson, 2019). They have also voiced their sadness because of their loss of control over their own life or their social life, which is consumed in the daily and constant raising of their grandchild (Hillman & Anderson, 2019). Following these identified

threats to the well-being of the grandparents, there is an indicated shift in research from the acknowledgement of the effects of caregiving stress on the well-being of grandparents to understanding how parenting grandparents can be better supported (Kresak & Gallagher, 2014).

## **2.7. Social Support of Grandparents Raising Their Grandchild with a Congenital Disability**

Social support has been defined as a transactional exchange of resources between two individuals, where there is a provider and a receiver of support (Shumacker & Brownell, 1984). From this concept of reciprocity, Cobb (1976) has highlighted three foundational points to the definition of social support, whereby information which is transmitted within the interaction leads to the receiver believing that they: i) are “cared for and loved”; ii) are “esteemed and valued”; and iii) “belong to a network of communication and mutual obligation” (Cobb, 1976, p. 300). These positive appraisals and beliefs stem from a subjective sense of social support (Cobb, 1976), which are closely linked to positive outcomes for mental health compared to the tangible receipt of social support (Thoits, 1995). Guralnick et al. (2008) have highlighted the need for research to view social support as a multi-dimensional construct. Studies have often conceptualised social support in terms of the network size and composition rather than also focusing on the functions of social support (Poon & Zaidman-Zait, 2014).

The multi-dimensional perspective of social support has been highlighted in a recent review by Mantri-Langeveldt, Dada and Boshoff (2019), where research on families raising a child with a disability considers social support as a construct with quantitative and qualitative characteristics. Quantitative characteristics are those which relate to the structure and number of supports available to the individual (Kresak et al., 2014) and how much support the network provides to the individual (Truesdale-Kennedy, Mcconkey, Ferguson, & Roberts, 2006). On the other hand, the qualitative characteristic of social support relates to what type of support the individual needs (Brand, Barry, & Gallagher, 2014), how helpful the support is to the individual (Kresak et al., 2014) and how satisfied the individual receiving the support is (Pfeifer et al., 2013). According to Barrera (1986), the qualitative functions of social support have been of greater importance in research pertaining to mental health constructs

(such as caregiving stress and well-being) as opposed to the quantitative traits of social support. To further understand the functions of social support to mental health, Vangelisti (2009) suggests the consideration of the sociological perspective and the psychological perspective. Table 2.3 provides the definition of the perspectives, the domains that are measured and the relationship between the perspectives and the construct of emotional well-being of the individual.

**Table 2.3: Theoretical Perspectives and Measures of Social Support**

	Perspectives of social support	
	Social perspective	Psychological perspective
Definition of perspective	The degree of integration of individuals within a social group (Vangelisti, 2009), social embeddedness in terms of the network and connections of the individual with members of their social environment who are significant to them (Barrera, 1986).	The behavioural phenomenon where an individual's cognitive appraisal or perception of their social network is considered (Barrera, 1986; Landry-Meyer, Gerard, & Guzell, 2008; Uchino, 2009) as well as what supports the individual identifies as the most important to them (Vangelisti, 2009).
Domain measured	The quantitative aspect of social support: (Thoits, 1995) <ul style="list-style-type: none"> <li>• Size of network</li> <li>• Structure of network</li> <li>• Sources of support in the network (formal and informal ties) (Fuentes-Peláez, Balsells, Fernández, Vaquero, &amp; Amorós, 2014).</li> </ul>	Qualitative characteristics of social support (Thoits, 2011) also known as perceived social support: <ul style="list-style-type: none"> <li>• Helpfulness of support received</li> <li>• Satisfaction of support received</li> <li>• Need for support (Thoits, 2011): <ul style="list-style-type: none"> <li>○ Emotional</li> <li>○ Informational</li> <li>○ Practical</li> <li>○ Tangible</li> </ul> </li> </ul>
Relationship to emotional well-being	A poor to non-existent relationship with emotional well-being (Barrera, 1986).	A strong relationship with emotional well-being (Vangelisti, 2009).

From Table 2.3, the psychological perspective, which is composed of the qualitative characteristic of social support, has been highlighted to possess a strong relationship with the emotional well-being of an individual (Vangelisti, 2009). This qualitative characteristic of social support has been further referred to as perceived social support in the general literature pertaining to the conceptualisation of social support (Barrera, 1986; Haber et al., 2007; Trivette et al., 1986; Vangelisti, 2009). Perceived social support is defined as the appraisal of the individual's availability of support and their global satisfaction with the support received; that is, how available social support is and how helpful the social support is in times of need (Thoits, 2011). However, for families, Trivette et al. (1986) have suggested that perceived social support should also consist of the perceived needs of the parent because meeting the

needs of the parent may lower the levels of stress and increase the well-being of the grandparent raising their grandchild (Trivette et al., 1986; Vangelisti, 2009). According to Trivette et al. (1986), individuals raising a child who is at risk innately strive to get their prioritised needs met. As a result, they may invest as much time and energy to get these needs met in a resourceful manner (Trivette et al., 2010). Therefore, the current study considers this perceived social support as a construct comprised of perceived need for types of social support and perceived helpfulness of the sources of social support available to the parenting grandparent.

### **2.7.1. Perceived needs for social support of parenting grandparents**

Research has shown that the perceived needs of the grandparents raising their grandchild with a disability are unique and tend to often be oriented towards better managing and understanding the disability of their grandchild (Miller, Buys, & Woodbridge, 2012). For example, Gallagher et al. (2010) found that the grandmothers in their study needed strategies on how to manage their grandchild's disability; for example, how to manage their aggression or the problem of the grandchild running away from the home. The grandparents also required ways to get their grandchild to communicate; they needed more information to better understand their grandchild's disability and prognosis and also needed respite because they were tired (Gallagher et al., 2010). The grandmothers expressed a need for resources such as specialised transportation, car seats, daily necessities as well as financial support in relation to their grandchild's special needs (Gallagher et al., 2010). The study by Gardner et al. (2004) revealed that the grandmothers in their study also needed emotional support as part of their co-parenting responsibility.

Grandparents raising their grandchild with a congenital disability may experience reduced opportunities to further invest resourcefully in caregiving due to the already prevalent intensive nature of caregiving (Trivette et al., 1986). Demirtepe-Saygili and Bozo (2011) also highlight that for social support to have a positive influence on a caregiver's psychological symptoms, the most basic needs of the caregiver need to be met. In accordance with Maslow's hierarchy of needs, if the basic needs are interrupted by the child's illness, or disability, the caregiver's psychological symptoms may persist, even if they perceive high levels of social support. Studies have shown that once the needs of the parenting grandparents have been met, reduced levels of depression are indicated (Brown et al., 2017; Gallagher et

al., 2010; McCallion et al., 2004) as well as an increase in parenting satisfaction (Kresak et al., 2014). Social support which meets the emotional needs of the grandparents has also been found to alleviate their concerns and worries about their grandchild and possible family conflicts they may experience (Brown et al., 2017; Gallagher et al., 2010; Gardner et al., 2004; Hillman & Anderson, 2019; McCallion et al., 2004).

### **2.7.2. Perceived sources of support of parenting grandparents**

Parenting grandparents have been identified to seek support from either informal sources of support, such as their friends or family and relatives (Gardner et al., 2004; Hillman & Anderson, 2019), or from formal sources of support such as organisations, support groups or services related to their grandchild's disability (Brown et al., 2017; Kresak & Gallagher, 2014; McCallion et al., 2004). These various sources of support provided helpful emotional, instrumental and financial support to the parenting grandparents. The comparative study by Kresak et al. (2014) of sole-parenting grandmothers raising a grandchild with and without a disability showed that the grandmothers raising a grandchild with a disability had a smaller amount of informal support than the other group of grandmothers. Grandmothers of grandchildren with a disability perceived the helpfulness of informal support to be less helpful compared to the grandmothers raising their grandchild without a disability. The grandmothers expressed that the challenges in managing the grandchild's disability-related behaviours reduced the involvement of their informal support. As a result, raising a grandchild with a disability may contribute to the social isolation of the grandparent compared to raising a grandchild without a disability (Kresak et al., 2014). This is cause for concern due to its indicated potential influences of social isolation on the well-being of grandparents (Hayslip, Fruhauf et al., 2017). For example, grandparents may experience emotional distress (S. J. Kelley, Whitley, & Campos, 2013), a sense of powerlessness (Cox & Miner, 2014), increased emotional withdrawal and depression (Janicki et al., 2000), lowered life satisfaction (Kresak et al., 2014) or heightened feelings of loneliness (Hayslip & Kaminski, 2005).

The causes for social isolation of grandparents have been indicated to be due to the full-time and intensive caregiving demands of their grandchild with a disability (Gordon, 2018; Hillman & Anderson, 2019; Kresak & Gallagher, 2014) or due to their strained relationships with family members and friends (Gordon, 2018; Hillman & Anderson, 2019). Grandparents



may also have low perceptions of belonging within their age-related peer groups due to their parenting responsibility (McCallion et al., 2004). They may also feel stigmatised by their age-peers and the community due to their grandchild's disability (Hillman & Anderson, 2018). The effect of support groups specific for grandparents raising grandchildren with a disability has been investigated in the literature. McCallion et al. (2004), for instance, found that the support group lowered the symptoms of depression of the grandparents. They also presented with improved sense of self-mastery and greater empowerment. McCallion et al. (2004) suspected that the support groups provided the grandparents with a sense of belonging. The study by Brown et al. (2017) also shows that the grandparents had better levels of physical well-being related to their health status, possibly due to the emotional support that the support group provided to the grandparents. However, McCallion et al. (2004) indicated the support group alone may not always be beneficial because some of the grandparents were not able to attend the support group due to the lack of respite. Parenting grandparents have expressed the need for respite in various other studies (Gallagher et al., 2010; Hillman & Anderson, 2019; Kresak et al., 2014; McCallion et al., 2004), where the lack of respite may sometimes be the reason for their being unable to access their social networks or the needed support.

Other than the perceived lack of availability of social support, it has been indicated that grandparents may also choose not to seek support when they experience stress and distress (Fuentes-Peláez et al., 2014). According to Uchino (2009), the decision to seek help and support from a network is dependent on the individual's emotions. These emotions would include, for example, feeling embarrassed about the problem, thinking and believing that they can manage their problems and knowing if the quality of their existing relationships is of such a nature that they have someone they can turn to in times of crisis. For example, when seeking support, grandparents have expressed that they may be turned down by friends and family because of the difficulty in managing the grandchild's disability-related behaviours (Hillman & Anderson, 2019). In some cases, parenting grandparents may also deplete their informal network by over-relying on their friends and family (Kresak & Gallagher, 2014). The quality of social support in terms of its perceived helpfulness may also determine whether the individual seeks support or not (Vangelisti, 2009). Therefore, even if an individual has an extensive social network and a large number of social connections, it may not necessarily mean that the social network helps the individual to cope with the stress (Barrera, 1986).

### 2.7.3. Perceived helpfulness of support of parenting grandparents

Trivette et al. (1986) highlight that the helpfulness of sources of support received is critical when supporting vulnerable families because there is a risk that social support may be counterproductive to the family if it does not match the needs of the parent. There have been indications that the perceived helpfulness of the social support may have an influence on the grandparent's satisfaction of caregiving and on their perception of their QoL (Kresak et al., 2014). For example, Kresak et al. (2014) showed that grandparents of children with a disability who have lower levels of informal support than grandparents of children without a disability found their informal support as being unhelpful. The grandmothers of children with a disability who reported to have unhelpful informal support also showed lower levels QoL and life satisfaction in comparison to the grandmothers raising their grandchild without a disability (Kresak et al., 2014).

Grandparents may also perceive formal support services as being unhelpful if they find it difficult to access the services, if the services are not individualised for their needs (Kresak et al., 2014) or if they do not receive support in terms of what intervention would be most suitable for their grandchild (Hillman & Anderson, 2019). The literature has shown that grandparents who take part in support groups devised for their unique needs as parents of a grandchild with a disability may have positive levels of well-being (Brown et al., 2017; McCallion et al., 2004). The grandparents may have greater ownership of the group sessions and be encouraged to attend the support groups because they have a sense of belonging (McCallion et al., 2004). It is also indicated that the support groups may provide the grandparents with the fundamental outlook on their situation, by knowing that they are not alone in this caregiving situation and could support each other through the process (Brown et al., 2017). From the indicated trend of literature regarding perceived social support, there is a growing interest in the possible mechanisms of whether and how perceived social support can alter the relationship between stress and well-being.

From reviewed literature, it is clear that research has recognised that the process of raising a grandchild with a disability has various effects on the grandparent's well-being. However, the depth in which the constructs of perceived social support, caregiver stress and well-being have been considered in combination is still lacking in this specific context. The literature review has provided an indication that parenting grandparents of a grandchild with a

disability are inclined to experience exacerbated levels of adverse effects from the stress they experience (e.g., higher risk of social isolation), and from the situation in which they find themselves as parents (e.g., greater financial strains). The reviewed studies also showed that the grandparents indeed present with unique needs and that the quality (e.g., helpfulness) of perceived social support may not always be conducive to having their needs met. Considering that childcare and consequent child developmental outcomes are at the heart of grandparents raising their grandchild with a disability, there are indications from the studies that there is a relationship between stress and the well-being of grandparents parenting their grandchild with a disability (McCallion et al., 2004). There are also indications of a relationship between the perceived social support, the well-being (Brown et al., 2017; Kresak et al., 2014; McCallion et al., 2004) and perceived social support on stress (Kresak et al., 2014; McCallion et al., 2004). Therefore, the current study hopes to explore the relationships between the perceived social support, stress and well-being of the grandparents as this has not as yet been explored in combination for this specific population of grandparents.

#### **2.7.4. The relationship between perceived social support, stress and well-being**

Two mechanisms that have been identified through which perceived social support can change the way that stress affects well-being are that of the moderating effect and the mediating effect. The moderating effect relates to reducing the effect of stress on the well-being by changing the parent's appraisal of the stressor in the presence of perceived social support (Cohen & Wills, 1985). It is also suggested that the moderating effect is present in stress, yet may be absent in distress (Cohen & Wills, 1985). The mediating effect, on the other hand, relates to reducing the effect of stress on the well-being of the grandparent through the indirect intervention of perceived social support (Quittner, Glueckauf, & Jackson, 1990). To date, these mechanisms have not been investigated in the context of grandparents raising their grandchild with a disability, or in the combination of perceived social support, caregiving stress and well-being. However, there are a limited number of studies which have looked specifically at the moderating and mediating effects of the combination of these three constructs.

Skok et al. (2006) explored the relationships between perceived stress, perceived social support and well-being in mothers raising a school-aged child with cerebral palsy. Their results show that perceived social support is a high predictor of well-being. That is, the

presence of high levels of perceived social support has a positive effect on the well-being of mothers, with a negative relationship between the perceived social support and perception of stress from the mothers. Sipal and Sayin (2013) further found that perceived social support has an inverse relationship to stress. The more social support the mothers of deaf children in their study perceived to have access to, the lower their levels of depression was and the higher their levels of psychological well-being. As a result of this reduced effect of stress on the parent, it can be assumed that the quality of the parent-child dyad relationship is due to improvements in the presence of perceived social support. This assumption is confirmed by McConnell, Breitzkreuz and Savage (2011), who found that higher levels of perceived social support in parents raising a child with a disability strongly diminished the effect of parenting stress with a more positive measured parent-child interaction.

In line with the DSA (Guralnick, 2011) and understanding the consequent relationship between the family patterns of interaction and child development outcomes, the lack of perceived social support on the child-related outcomes has further shown the importance of perceived social support as a resource to parents. This is demonstrated by McManus and Poehlmann (2011), who found that in absence of perceived social support, mothers in their study reported having higher levels of post-natal depression. This resulted in a measured lowered cognitive functioning of their infant within the first three years of life. Therefore, in light of the findings of these studies, identifying the mediating and moderating effects of perceived social support will determine whether this construct has the ability to maintain the emotional well-being of grandparents raising their grandchild with a congenital disability. To date, there has been a paucity of studies which consider the relationship between perceived social support (measured as both the perceived need for types of support and the perceived helpfulness of support) and stress and well-being in the context of grandparents raising their grandchild with a congenital disability.

This review has highlighted that, contextually, there is a paucity of research and published literature exclusive to grandparents of children with a disability in South Africa. However, from the literature on general parenting grandparents in South Africa (Dolbin-Macnab et al., 2016; Hanass-Hancock & Casale, 2014; Hanass-Hancock, Gwezera, Mudekunye, Alufandika, & Byamukama, 2013), it is inferred that parenting grandparents may be experiencing stress and greater strains to their well-being, with a lack of social support due to high levels of social isolation. However, these South African based studies have also

highlighted that parenting grandparents experience a further strain due to the indicated prevalence of poverty and lack of resources (Hanass-Hancock & Casale, 2014). It is postulated that the lifelong implications of disability may have been underestimated in such a context of literature. This necessitates the need to look closer at how the grandparents can be more effectively supported through social support specific to their needs and in the context of their grandchild's congenital disability. Therefore, the current study seeks to contribute to an understanding of the caregiving stress, well-being and perceived social support of grandparents in the South African context.

## **2.8. Summary**

This chapter provided a review of the literature on parenting grandparents raising a grandchild, followed by a proposed adaptation of the framework of the DSA with a discussion of literature based on parents raising a child with a disability. Details of a systematic search of literature were provided specific to grandparents raising their grandchild with a congenital disability. The relationship between stress, well-being and social support was discussed in light of the literature specific to this population of grandparents. Following this, the literature in relation to the constructs of stress, well-being and social support was discussed. This was followed by the available literature on the mediating and moderating effects of perceived social support on the relationship of stress and well-being and how this could apply to the context of a grandparent raising their grandchild with a congenital disability.

## Chapter 3: Identification and Adaptation of Measures

### 3.1. Introduction

This chapter provides details of Phase 1 and Phase 2 of the material adaptations (Figure 3.1).

Phase 1 of the study involves the process of identifying and selecting the measures to be used in the study. Phase 2 of the study considers the adaptations which were made to the materials used in the survey. The adaptations are described in terms of the content and context modifications, followed by the translation process into isiXhosa and Afrikaans, in addition to English. Finally, a description is provided regarding adaptations with graphic symbols for the measures.

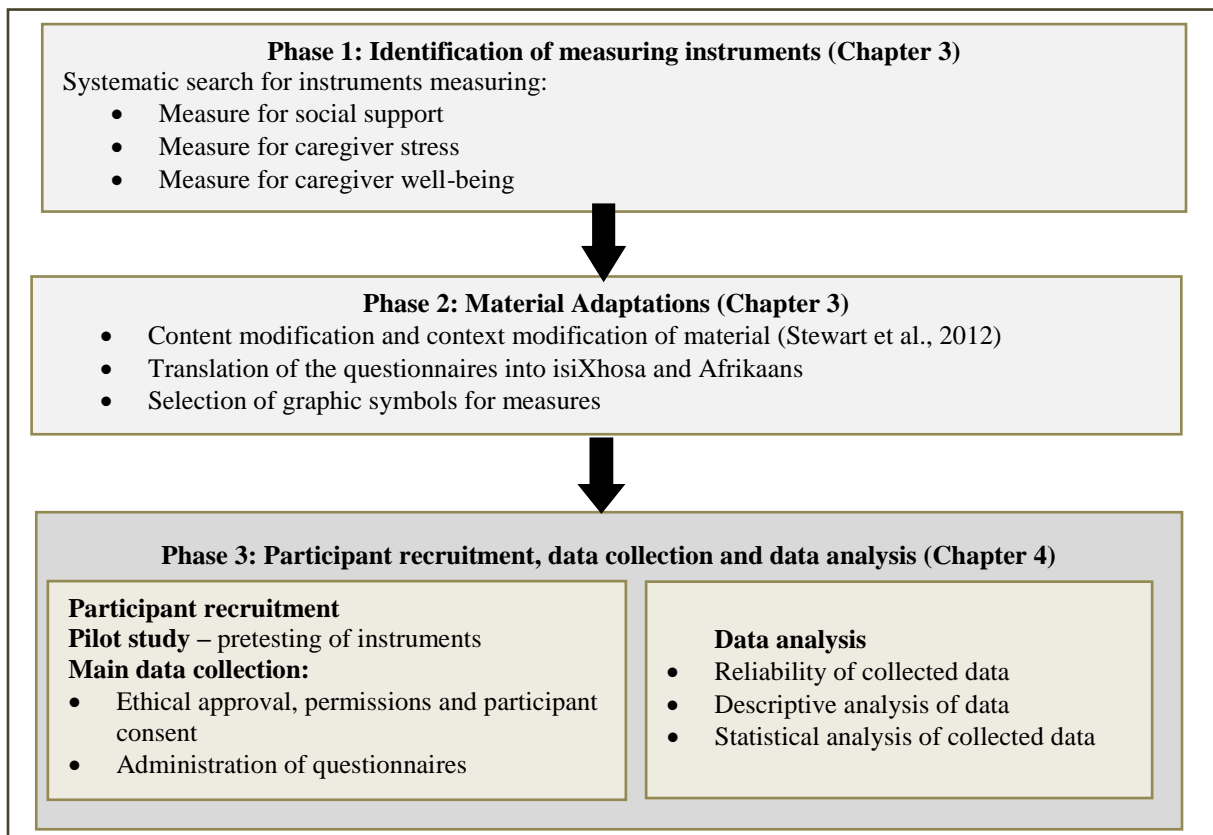


Figure 3.1: Phases of Study

## 3.2. Phase 1

Phase 1 of the study was comprised of the identification and selection of the measures of caregiving stress, well-being and social support through a systematic search of the literature.

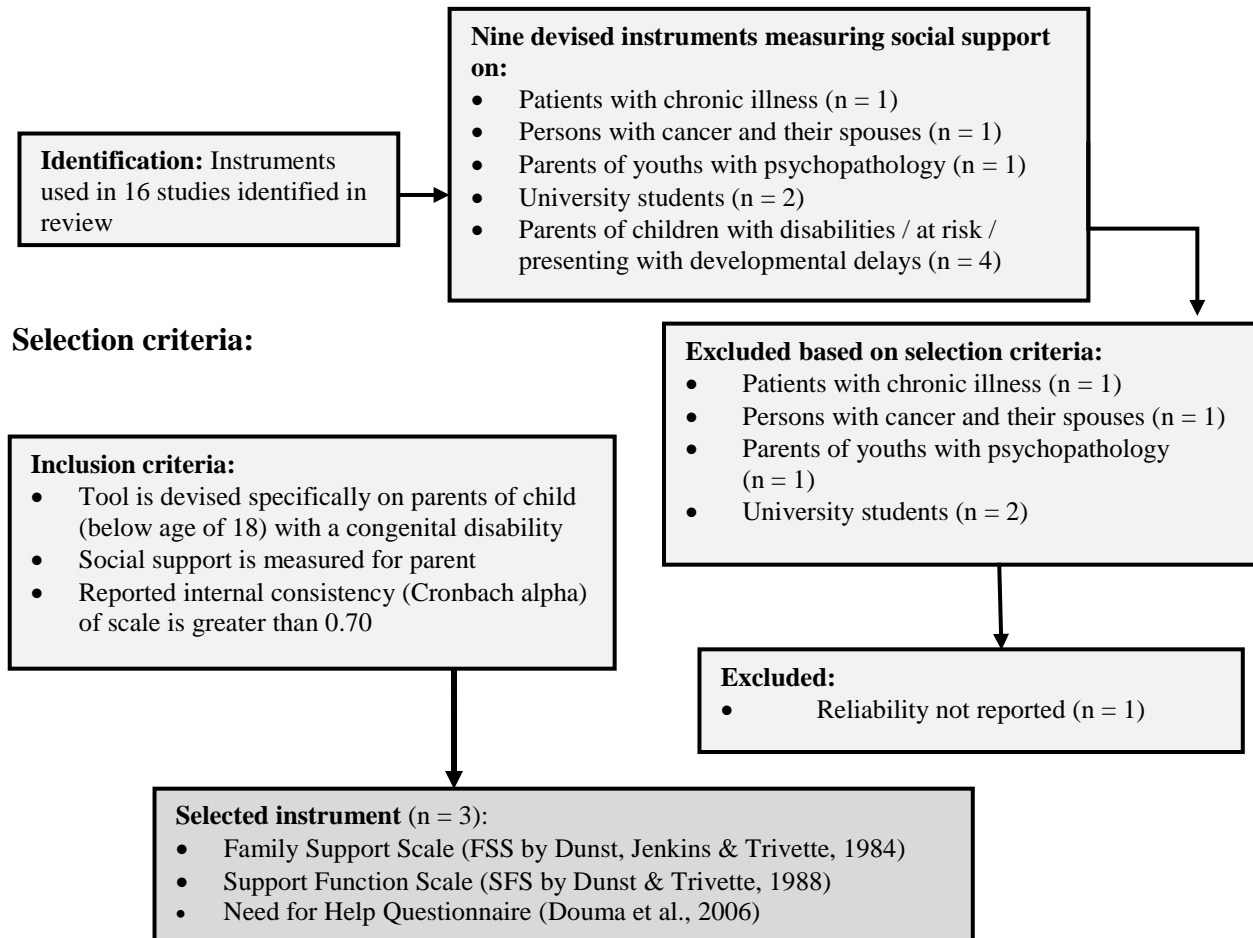
### 3.2.1. Systematic searches for measuring instruments

The aim of the systematic search was to identify an instrument for measuring caregiving stress, well-being and social support for grandparents raising a grandchild with a disability as used in previous quantitative studies. Specifically, the search for instruments for measuring each construct required that: i) the instrument was a short questionnaire containing no more than 20 items, considering the amount of time each questionnaire will take to be completed (Irwin & Stafford, 2016); ii) the questionnaire was aimed at measuring either caregiving stress, caregiver well-being or social support and; iii) the questionnaire was developed for the caregivers raising a child with a disability.

#### 3.2.1.1 Systematic search for social support measures.

A scoping review was conducted to identify questionnaires on social support for the current study (Mantri-Langeveldt et al., 2019). The key terms used for the search were: “support” AND “scale\*” OR “measure\*” AND “parent\*” OR “kinship\*” OR “grand\*” AND “child\*” AND “disab\*”. The EbscoHost and Scopus search engines were used. Ten computerised databases were searched, namely *Academic Search Complete*, *Africa-Wide*, *CINAHL*, *E-Journals*, *ERIC*, *Family & Society Studies Worldwide*, *Health Source-Nursing/Academics Edition*, *MEDLINE*, *PsychINFO* and *Social Work Abstracts*. For each database, limiters were set to filter only English quantitative journal articles that were available in full text between 1980 and 2015. The criteria for the selection of the journals were that: i) the measure was in a questionnaire format; ii) the questionnaire was in English; iii) the aim of the questionnaire was to measure social support for parents or grandparents raising a child with a congenital disability; iv) the measure was devised on either parents or grandparents raising a child with a disability; v) the measure was comprised of 20 or less items; vi) the items and questions were easy to understand by people with low levels of literacy (Cremers, Welbie, Kranenborg, & Wittink, 2015) and; vii) the measure was accessible online. A total of 16 studies were included in the review, from which nine measures were

selected (Figure 3.2) using the set inclusion criteria. A total of 3 measurement tools were identified to measure the perceived types of support needed (Support Functions Scale – SFS by Dunst & Trivette, 1986, see Appendix C), the availability and helpfulness of support from various sources (Family Support Scale – FSS by Dunst, Trivette, & Jenkins, 1984, see Appendix D) and the need for support seeking (Need for Help Questionnaire by Douma, Dekker, & Koot, 2006).



**Figure 3.2: Selection Process of Social Support Measures**

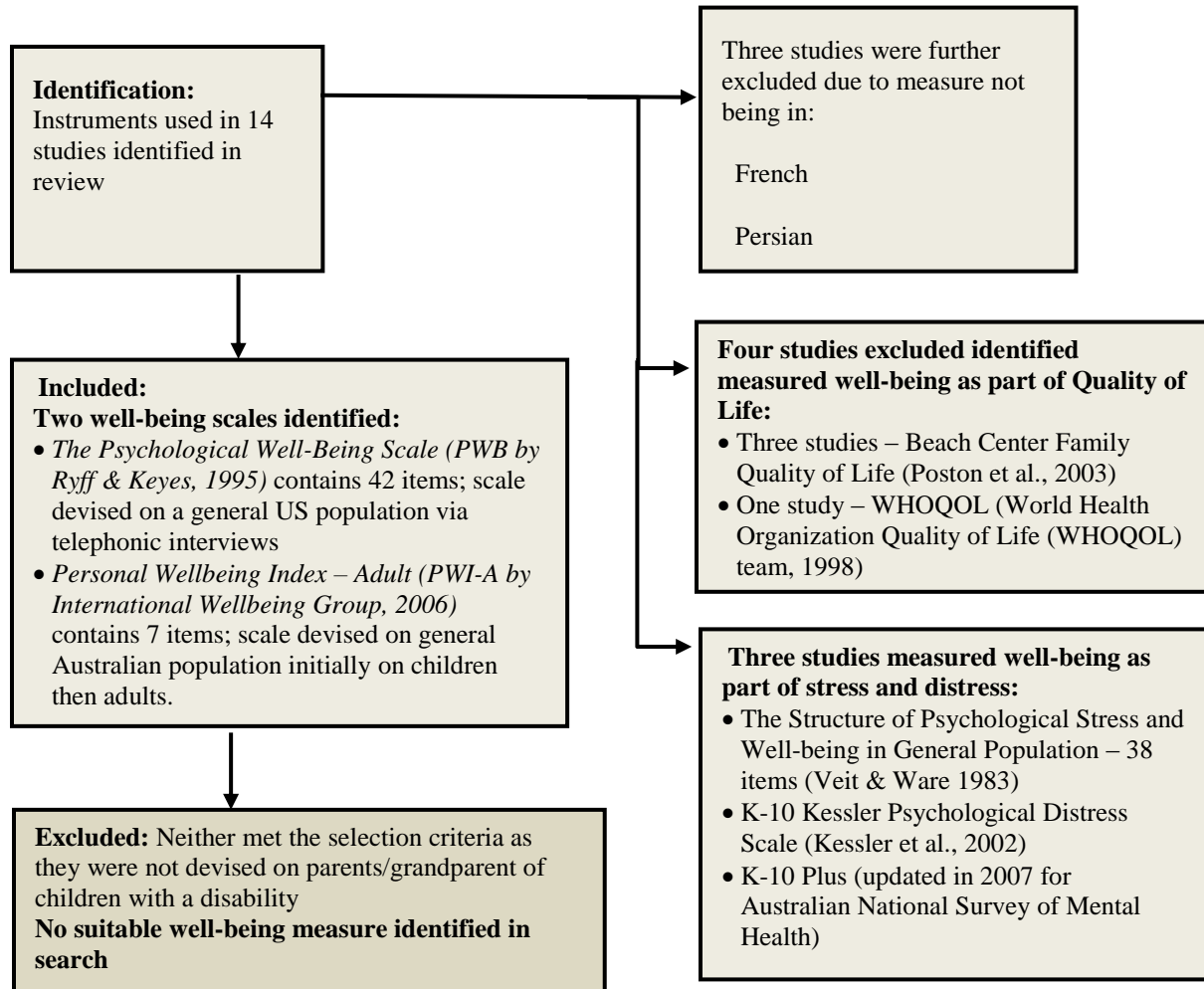
From the three questionnaires identified in the review, only two measures, namely the Support Functions Scale (SFS) (Dunst & Trivette, 1988) and the Family Support Scale (FSS) (Dunst, Jenkins & Trivette, 1984) were selected due to their online availability as complete questionnaires. Permission was obtained from Winterberry Press (Appendix E) to use and adapt



the SFS and FSS in the current study for the population of grandparents with varying levels of literacy. Further information regarding the adaptation of the SFS and FSS follows in section 3.3.

### 3.2.1.2 Systematic search for well-being measures

The aim of this systematic search was to identify a suitable measure for well-being of the grandparent caregivers in the current study. The key terms which were used were: “parent\*” AND “well-being scale” AND “measure” AND “child\*” AND “disab\*” AND “grand\*” AND “kinship\*”. The following databases were searched: *Academic Search Complete, Africa-Wide Information, CINAHL, E-Journals, ERIC, Family & Society Studies Worldwide, Health Source-Nursing/Academics Edition, MEDLINE, PsychINFO* and *Social Work Abstracts*. The limiters in each database were set to filter only English quantitative journal articles which were available in full text and between 1980 and 2015. The selection criteria were as follows: i) the well-being measure was in a questionnaire format; ii) the questionnaire was in English; iii) the aim of the measure was to identify the positive and negative aspects of well-being (Pruchno & McKenney, 2002) when raising a child with a congenital disability; iv) the measure was devised on either parents or grandparents raising a child with a disability, v) the measure was not more than 20 items; iv) the items and questions were easy to understand by people with low levels of literacy (Cremers et al., 2015); vii) the well-being measure has a reported reliability of greater than 0.70 (Kline, 2011) and viii) the measure was accessible online. The search resulted in a total of 78 articles, of which 64 were found to be irrelevant, leaving 14 that met the selection criteria. The full-text articles of the 14 studies were analysed for the well-being scale used. The results of the search are illustrated below in Figure 3.3.

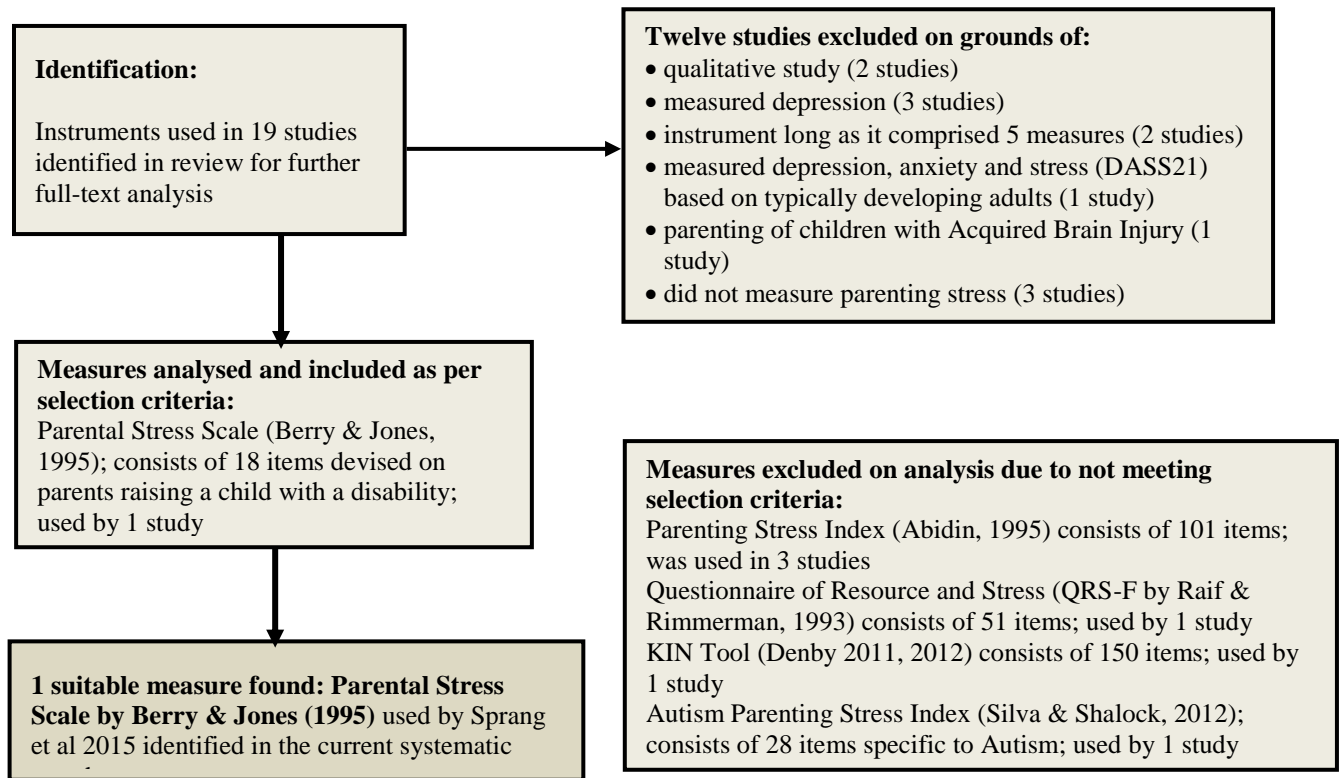


**Figure 3.3: Selection Process of Well-Being Measure**

Following the unsuccessful identification of a well-being measure, a search on the Winterberry Press was carried out due to the various family and childhood disability questionnaires which were identified on the online platform in conjunction with the SFS and FSS. As a result, the Personal Well-Being Index (PWBI) devised by Trivette and Dunst (1986) (see Appendix B) was identified. The PWBI was considered to be a suitable match for the current study as it met all the selection criteria. It was also available from the Winterberry Press as a complete measure. Further information regarding the adaptation of the scale is described in section 3.3.

### 3.2.1.3 Systematic search for stress measures.

The current systematic search aimed to identify a measure for stress applicable to the parenting grandparents of this study. The following search terms were used: “parent\*” AND “stress scale\*” AND “measure\*” AND “child\*” AND “disab\*” AND “grand\*” AND “kinship\*”. As in the previous systematic searches, the following databases were searched: *Academic Search Complete, Africa-Wide Information, CINAHL, E-Journals, ERIC, Family & Society Studies Worldwide, Health Source-Nursing/Academics Edition, MEDLINE, PsychINFO* and *Social Work Abstracts*. Limiters were set in each database to filter only English quantitative journal articles which were available in full text and written between 1980 and 2015. The selection criteria were as follows: i) the parenting stress measure was in a questionnaire format; ii) the questionnaire was in English; iii) the aim of the questionnaire was to measure the parenting stress of either parents or grandparents raising a child with a congenital disability; iv) the measure comprised of a minimum of 20 items; v) the items and questions were perceived by the researcher to be easy to understand by people with low literacy (Cremers et al., 2015); vi) the measure had a reported reliability of greater than 0.70 (Kline, 2011); and vii) the measure was accessible online as a complete measure. The search resulted in 47 articles, from which 40 were excluded due to their irrelevance and 7 were further analysed for their instruments (Figure 3.4).



**Figure 3.4: Selection Process of Parenting Stress Measure**

Through the systematic search, the Parental Stress Scale (PSS) (Berry & Jones, 1995) was identified and found suitable for use in the current study as it met all the selection criteria. The adaptation of the scales will be discussed in more detail in section 3.3.

### 3.3. Adaptations to the Measures Used in the Study

The four self-reporting questionnaires identified for the study, namely the PSS, the PWBI, the SFS and the FSS, were modified to suit the varied levels of literacy of the grandparent participants of the study (Research Center Survey, 2016). It was important to modify these measures so as to include a diverse population of grandparent participants, namely, those speaking English, Afrikaans, and isiXhosa, the predominant languages spoken in the Western Cape (Sweetnam Evans, 2015) as well as those with low levels of literacy (Stewart, Thrasher,

Goldberg, & Shea, 2012). The linguistic equivalence of the measures was ensured while measuring the required variables to retain the validity of the measure (Peña, 2007). The modifications made to the measures were guided by the framework of Stewart et al. (2012) specific to the content, context, presentation and translation of each measure as described in section 3.4.1.

### **3.3.1. Content modifications of the measures**

Content modification involved adaptations which were made “at the level of dimensions, items, or response options, all of which can be added, dropped, modified, or replaced” (Stewart et al., 2012, p. 999). Accordingly, the researcher carried out the content modifications for the four measures (see Table 3.1 and Appendix F), only for those items which were double-barrelled in nature, requiring the item being split into two separate items to avoid confusion in the participants (Lederer, Comber, & Oswalt, 2014). Items were added to the existing scale, based on the domains being measured which are supported by literature specific to the South African or Western Cape grandparent population of the study. The low levels of literacy prevalent in the grandparent population of South Africa (Statistics South Africa & Lehola, 2014a) informed the need for the researcher to also carry out content modifications to the Likert scales of the measures where applicable.

Available literature (Bernal, Wooley, & Schensul, 1997) on the use of Likert scales on populations of low levels of literacy cautions against the use of response scales containing more than four responses, as this may frustrate or confuse the participant (Bernal et al., 1997). As a result, the Likert scales of the PWBI, the SFS and the FSS were modified. The Likert scale of the PSS was not modified because it was an agreement scale in nature, where all the five options were critical in weight in detecting the construct being measured in the item (Weijters, Cabooter, & Schillewaert, 2010). The Likert scales of the PWBI and the SFS were reduced from a 5-point to a 4-point scale, and the scale of the FSS was reduced from a 6-point scale to a 5-point scale (see Table 3.1 and Appendix F). The decision on which response of the scale to drop was determined by which response option had a slight semantic variation, as options that have minimal variations in meaning may create confusion in participants with low literacy levels

(Sousa & Rojjanasrirat, 2010). In addition, the translation process further supported the decision of which response to drop. For example, the IsiXhosa translators reported that it was challenging to find an equivalent translation to “often” as it was similar in meaning to “quite often” in isiXhosa. Therefore, the option of “quite often” was dropped and the option of “often” was retained as the extreme positive end of the frequency scale. The same rationale was applied for the FSS between the options of “very helpful” and “extremely helpful” and the option “very helpful” was therefore dropped and the option of “extremely helpful” was retained to represent the extreme positive end of the scale.

**Table 3.1: Content Modifications Made to Measures According to Framework by Stewart et al. (2012)**

Scale	Content modification to original items	Content modification to Likert scale
Parental Stress Scale (Berry & Jones, 1995b)	Items split as they were double-barrelled, for example: <ul style="list-style-type: none"> <li>• Original item 4: Having child(ren) has meant having too few choices and too little control over my life</li> <li>• Original item 6: The behaviour of my child(ren) is often embarrassing or stressful to me</li> </ul>	No changes made to Likert scale
Personal Well-Being Index (Carol M. Trivette & Dunst, 1986)	No content modification to items required	Option of “quite often” dropped due to complexity in understanding slight semantic variation between “often” and “quite often” when translated (Sousa & Rojjanasrirat, 2010). Scale was reduced from 5 to 4 response options.
Support Functions Scale (Dunst & Trivette, 1986)	No content modification to items required	Option of “quite often” dropped due to complexity in understanding slight semantic variation between “often” and “quite often” when translated (Sousa & Rojjanasrirat, 2010). Scale was reduced from 5 to 4 response options.
Family Support Scale (Dunst et al., 1984)	Items added to represent the dimensions in the South African context for availability and helpfulness of: <ul style="list-style-type: none"> <li>• other grandchildren due to evidence in literature that grandparents in South Africa are often raising more than one child in their household (Schatz et al., 2015);</li> <li>• a nanny, as some grandparents may have a nanny to care for the child when they have to work (Simson, 2013);</li> </ul>	Option of “very helpful” was dropped due to complexity of slight variation (Sousa & Rojjanasrirat, 2010) between “generally helpful” and “extremely helpful” when translating into isiXhosa. Scale was reduced from 6 to 5 response options.

Scale	Content modification to original items	Content modification to Likert scale
	<ul style="list-style-type: none"> <li>• an employer for those grandparents who are still working and who rely on their employer for a salary (Statistics South Africa &amp; Leholo, 2014);</li> <li>• other grandparents raising a grandchild with a disability as grandparents often form close connections with other grandparents who are in a similar situation as caregivers (Kirby &amp; Sanders, 2012);</li> <li>• item of helpfulness of ECI programme merged with professional services, as in the South African context, most ECI programmes would be accessed as part of hospital services.</li> </ul>	

### 3.3.2. Context modifications of the measures.

Context modifications involved adaptations made to the measure that matched the specificity of the participants in the study (Table 3.2). Adaptations pertained to, for instance, modifications to the instructions or changes in the administration of the measure (e.g., from reading to listening), modifying terms (e.g., changing “child” to “grandchild”), changing the appearance of the measure (e.g., adding visuals support) or changing the method of response (e.g., from written to pointing). Additional content modifications made to some of the measures related to the recall time, which was increased to improve the participants’ accuracy of recall (Stewart et al., 2012). For example, instead of using the recall time of only two weeks in the PWBI, the time frame of “since the beginning of the month” was added, since most grandparent caregivers would receive and access their financial support grant, their salary or their pension funds during that time, which would enable them to better recall how they felt at that time. Finally, the incomplete statements from the original measures were modified to be a complete question or a complete sentence because each item would be read to the grandparents in an interview format.

**Table 3.2: Context Modifications Made to Measures According to Framework by Stewart et al. (2012)**

Scale	Context modification to original items	Context modification to Likert Scale	Context modification to Instructions
Parental Stress Scale (Berry & Jones, 1995b)	<ul style="list-style-type: none"> <li>• Wording of items modified for “child” to “grandchild with a disability”.</li> <li>• Referent changed from “I” to “you” for each item to be read aloud, for instance from: “I am happy in my role as a parent” to “You are happy in your role as a caregiver of your grandchild with a disability”.</li> <li>• Graphic symbols for each item stem used as visual support for the participants.</li> </ul>	Visual support provided for participant to point to.	Instructions modified: <ul style="list-style-type: none"> <li>• specific to grandparent participants</li> <li>• from self-completion instructions to verbal instructions with pointing to response on Likert scale</li> <li>• to include possible responses.</li> </ul>
Personal Well-Being Index (C. M. Trivette & Dunst, 1986)	<ul style="list-style-type: none"> <li>• Recall period modified from two weeks to include the beginning of the month to improve the accuracy of recall of the participants (Stewart et al., 2012).</li> <li>• Wording of items modified to reduce linguistic complexity and to improve comprehension of ambiguously worded items (Siniscalco &amp; Auriat, 2005), for example:               <ul style="list-style-type: none"> <li>- Item 4: from “... under-the-weather or ill” to “... unwell or ill”</li> <li>- Item 6: from “... tired or fatigued after ...” to “... felt tired or exhausted after ...”</li> <li>- Item 10: from “... to get things done” to “... to get things done (e.g., household chores)”</li> <li>- Item 11: from “... feeling blue or depressed” to “... felt down or depressed”</li> <li>- Item 14: from “... on top of the world” to “... felt really happy”</li> <li>- Item 16: from “... in tip-top shape” to “... feeling like I am in great shape”.</li> </ul> </li> <li>• Referent changed from “I” to “you” in each item to be read aloud.</li> <li>• Time reference added for each item to remind participant of timeframe of answer: for example, “<i>Since the beginning of the month</i>, how often have you felt that your life is going just great?”</li> <li>• Graphic symbols for each item stem used as visual support for the participants.</li> </ul>	Visual support provided for participant to point to response. Likert scale label changed to increase clarity, for instance: from “ <i>Never</i> ” to “ <i>You never felt like this</i> ”.	Instructions modified to: <ul style="list-style-type: none"> <li>• specific to grandparent participants</li> <li>• from self-completion instructions to verbal instructions with pointing to response on Likert scale</li> <li>• reference to time frame “since the beginning of the month / past two weeks” added to each item.</li> </ul>



Scale	Context modification to original items	Context modification to Likert Scale	Context modification to Instructions
Support Functions Scale (Dunst & Trivette, 1986)	<ul style="list-style-type: none"> <li>• Wording of items modified, for example from “Someone to talk to about things that worry you” to “How often do you feel you need someone to talk to about things that worry you?”</li> <li>• Referent changed from “I” to “you” in each item to be read aloud.</li> <li>• Items modified from a statement to a question to be read aloud to participant.</li> <li>• Graphic symbols for each item stem used as visual support for the participants.</li> <li>• Wording of items modified to reduce linguistic complexity and to improve comprehension of ambiguously worded items (Siniscalco &amp; Auriat, 2005), for example: - Item 11: from “Someone to hassle with agencies ...” to “... Someone to follow up with SASSA ...”</li> </ul>	<p>Visual support provided for participant to point to response.</p> <p>Likert scale label changed to increase clarity, for example: from “Never” to “You never need this help”.</p>	<p>Instructions of measure modified:</p> <ul style="list-style-type: none"> <li>• from self-completion instructions to verbal instructions with pointing to response on Likert scale</li> <li>• to include possible responses.</li> </ul>
Family Support Scale (Dunst et al., 1984)	<ul style="list-style-type: none"> <li>• Wording of items modified, for example: from “My spouse or partner” to “How helpful has your husband/wife or partner been?”</li> <li>• Referent changed from “my” to “your” in each item to be read aloud.</li> <li>• Recall period changed from “3 months” to “6 months” to “past 6 months” to improve the accuracy of recall of the participants (Stewart et al., 2012).</li> <li>• Graphic symbols for each item stem used as visual support for the participants.</li> </ul>	<p>Visual support provided for participant to point to response.</p>	<p>Instructions of measure modified:</p> <ul style="list-style-type: none"> <li>• from self-completion instructions to verbal instructions with pointing to response on Likert scale</li> <li>• reference to timeframe: “Since the past 6 months ...” added to each item.</li> </ul>

### 3.3.3. Translation process.

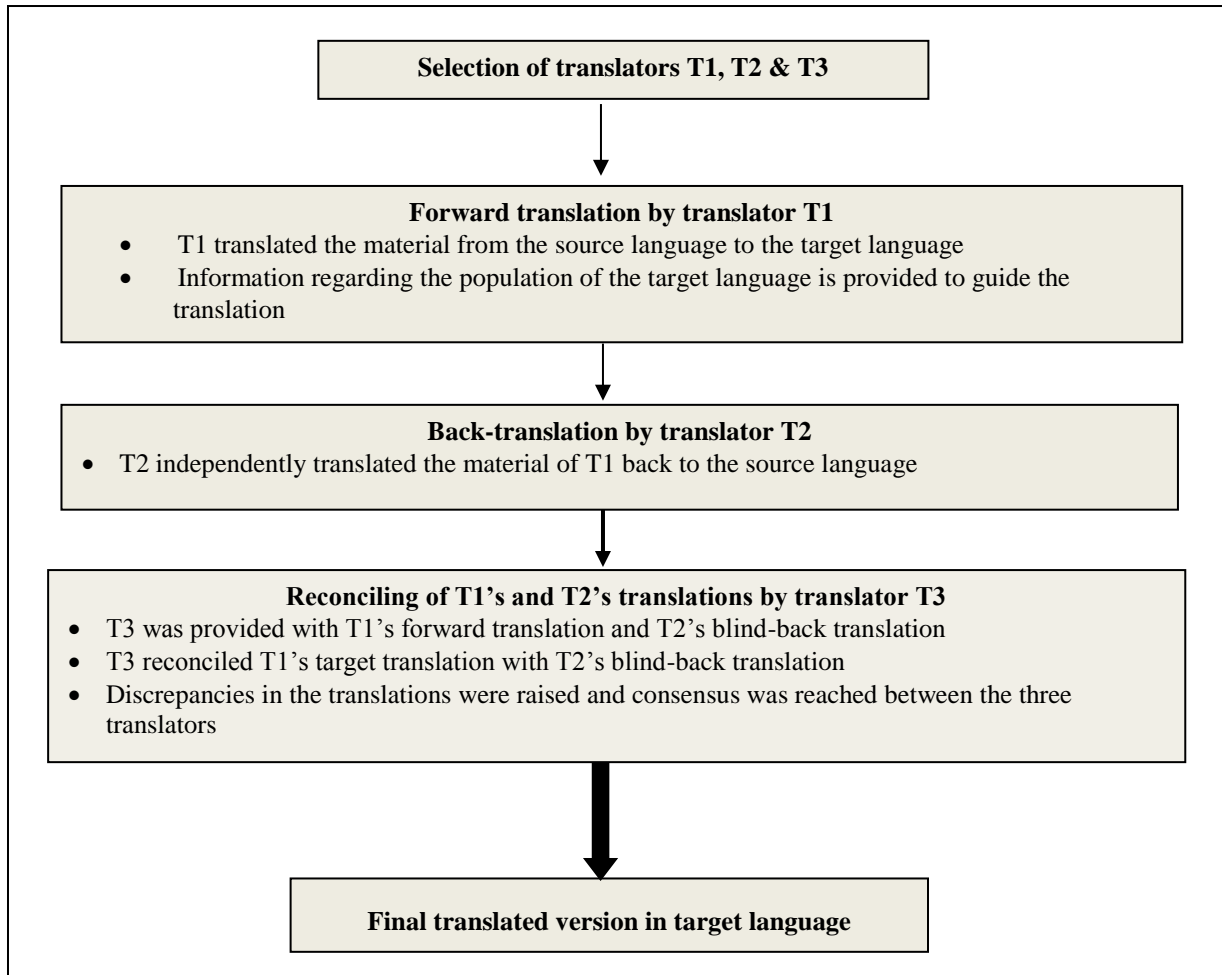
To accommodate the grandparents who do not speak English as a first language and due to the diverse demography of the South African population, the measures used in the study were translated and culturally adapted. In the Western Cape, isiXhosa and Afrikaans are the two main languages spoken as an alternative to English (Sweetnam Evans, 2015). The materials that were translated were those used in Section A (invitation letter, consent form, biographical form and Ten Questions Questionnaire (TQQ) screening tool (Appendices H1, H2 and H3) and Section B of the measures PSS, PWBI, SFS and FSS (Appendices I1, I2, I3).

The translation process followed in the current study was guided by the back-translation framework by Brislin (1986). The back-translation framework was considered as it takes into account the multi-cultural context in which the measure needs to be applied (Brislin, 1986). The aim of the translations was to ensure that the concepts which are meant to be measured by the instrument and the linguistic equivalence of the measures were preserved (Brislin, 1986). Therefore, in spite of the translation, the linguistic meaning from the original instrument would be equivalent to the meaning in the translated version (Brislin, 1986). A further aim was to adapt the measures to the culture in which it will be used by ensuring that the concepts were appropriate to the target language group (Brislin, 1986). A total of six translators took part in the translation process, where three translators carried out the isiXhosa language translation process and three other translators carried out the Afrikaans translation process. Four of the six translators were considered on grounds of being fluent in their home language ( $n = 3$  in isiXhosa and  $n = 3$  in Afrikaans) and in English as well as due to their work experience within the communities around South Africa. The other two translators were considered due to their qualifications as language practitioners. The details of the translators are presented in Table 3.3.

**Table 3.3: Description of Translators**

	<b>Translator 1 (isiXhosa)</b>	<b>Translator 2 (isiXhosa)</b>	<b>Translator 3 (isiXhosa)</b>	<b>Translator 1 (Afrikaans)</b>	<b>Translator 2 (Afrikaans)</b>	<b>Translator 3 (Afrikaans)</b>
<b>Qualification/s</b>	Bachelor in Arts BA Honours Development Studies Masters in Social Science	CEFA (Social Auxiliary Worker)	Master's degree in African Language and Literature	BSc Nursing	Matric	BA Afrikaans & Nederlands, English, Psychology Postgraduate Diploma in Translation
<b>Occupation</b>	Research, M&E and Systems Officer	Social Auxiliary Worker	Project co- ordinator at the Multilingual Education Project (University of Cape Town)	Nursing Manager	Administrative Clerk at Police Head Quarters and Post Office	Freelance translator and secretary
<b>Work experience</b>	15 years as Research and M&E	20 years: as research assistant, social auxiliary worker, facilitator, safe house supervisor and childcare worker	5 years: as teaching second language isiXhosa, translating and transcribing	26 years: as Public Health Care (PHC) nurse, chief community health nurse, deputy director PHC clinic operations	4 years	12 years: as full-time translator and part-time secretary
<b>Mother tongue</b>	isiXhosa	isiXhosa	isiXhosa	Afrikaans	Afrikaans	Afrikaans
<b>Other languages</b>	English	English and Afrikaans	English and Afrikaans	English	English	English
<b>Translation experience</b>	15 years	14 years	5 years	26 years as practical experience as part of work	1 year (informal experience)	15 years

In the translation process (Figure 3.3), the original language of the measure is referred to as the “source language” and the “target language” refers to the language to which the measure needed to be translated (Brislin, 1986). Therefore, in the current study, the source language was English and the target languages were isiXhosa and Afrikaans.



**Figure 3.5: Translation Process of Material (Brislin, 1986)**

As per Figure 3.5, the T1 translators of both target languages forward-translated the material from English to the target language. Translator T2 back-translated T1's version from the target language back to English. Translator T3 then reconciled and synthesised both T1's forward-translation and T2's back-translation to create the final translated version in the target language. Continued discussions were held with the three translators regarding the cultural appropriateness of the translated items to ensure that the translations were appropriate for grandparent caregivers of both target language groups. This cross-cultural translation process (Brislin, 1986) was pivotal in ensuring that the scale would be culturally valid and contextually understood by the participants of the isiXhosa group. The final

translated questionnaire items were then piloted on two IsiXhosa and two Afrikaans speaking grandparent caregivers to ensure that the items were well understood and clear (Brislin, 1986). The outcomes of the pilot study related to the translations are provided in Chapter 4 in Table 4.4 and Table 4.5.

### **3.3.4. Graphic symbols for the measures**

The measures were further modified with the addition of graphic symbols to the text of each item and Likert scale responses to the measures. The use of the graphic symbols was to serve as a visual support to the items and Likert scales presented verbally to the participants (Batorowicz, King, Vane, Pinto, & Ragavendra, 2017). Graphic symbols as a form of visual support have been found to be a useful tool when carrying out surveys with populations where low levels of literacy are prevalent (Cremers et al., 2015). The graphic symbols represented the main concept of the item and of each response of the Likert scale.

#### *3.3.4.1 Selection process of graphic symbols*

A graphic symbol which had the closest representation to the core concepts of the items and was identified on the online website of Bildstod™ ([www.bildstod.se](http://www.bildstod.se)) created by DART – the Centre for Augmentative and Alternative Communication and Assistive Technology in the project KomHIT – was used in this study. This website contains a variety of symbols from different systems to create picture-based material for information and communication. The reason for using these graphic symbols compared to, commercially available Picture Communication Symbols (PCS), is due to it being freely available as well as the large library of Bildstod symbols which are appropriate for the adult population. Furthermore, the Bildstod symbols did not require clustered illustrations to represent a concept (Weiner et al., 2004).

The researcher selected the graphic symbols. The process of selection involved keyword searches from the website for each of the graphic symbols. However, the exact concept words for each item of the questionnaire did not always produce results. To ensure that the searches were correct, the input was provided from a member of the development team at DART (U. Ferm, personal communication, February 1, 2018). Input was provided on the types of pictures to use and where a mix of black and white as well as colour symbols was deemed suitable. Furthermore, U. Ferm (personal communication, February 1, 2018) also advised the

researcher to use as many English and Swedish derivatives of the words or morphemes when carrying out the search of the graphic symbols. Therefore, the researcher used the online Google Translate for the Swedish derivatives. On certain occasions, broad search words, such as “have”, “not”, “do”, were used to deliver a larger variety of symbols linked to vocabulary of either Swedish words or English words or parts of words containing the search term. The researcher selected the graphic symbols which she thought best represented the core concept of the survey items.

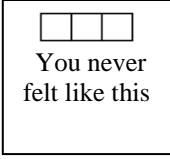
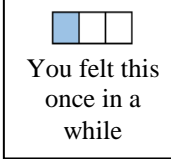
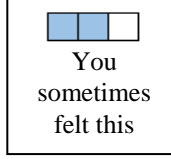
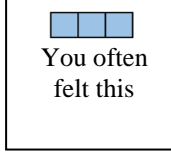
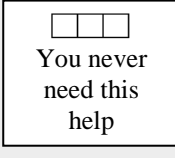
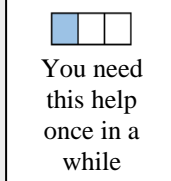
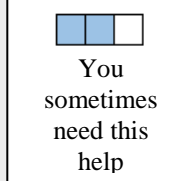
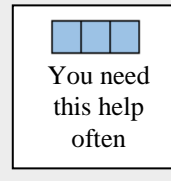
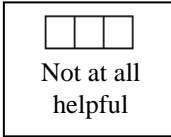
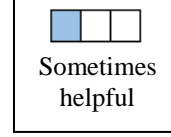
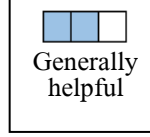
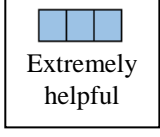
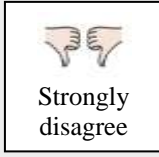

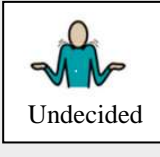
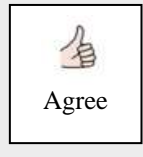

To ensure the validity of the graphic symbols to the current population of the study, a speech therapist who is a qualified Augmentative and Alternative Communication specialist with nine years of practical experience assisted the researcher to establish face validity of the graphic symbols. She was asked to compare the survey items in the original measure to the modified items accompanied by their graphic symbols. She then provided feedback regarding the representation equivalence of the graphic symbol to the item of the measure. Discussion with the therapist was especially beneficial for those graphic symbols which required further detailing to bring its representation as close as possible to the core concept of the item. In Appendix G, the justifications for using the specific graphic symbols for each item of the measures are described.

Some of the items of the measures had emotions as a core concept (e.g., depressed, happy, tired). To determine whether a black and white symbol or a colour face symbol should be used, the researcher was advised (U. Ferm, personal communication, February 1, 2018) to ask a person with a low level of literacy to indicate which one would be most representative. The reason for seeking specific input for the representations of the emotions was to ensure that graphic symbols were clearly understood and appropriate for the adult population (Cremers et al., 2015). The person with low literacy was therefore given a choice between the black and white symbol and a colour face symbol. Further input was provided to the researcher regarding the graphic symbols representing some of the sources of social support, for example, husband/wife in the FSS. Following these validity procedures, the graphic symbols were added to the text of each item.

Graphic symbols were also used to support the text labels of the Likert scale response as visual support in each measure (see Table 3.4 and Appendix F). The Likert scales of the PWBI and the SFS were frequency scales by nature. The graphic symbols used as visual

support for the participants were in the form of blocks graded from empty for the option of “never” to partially shaded for the option of “sometimes” to completely shaded in blue for the option of “often”. This set of graphic symbol was previously used by Bernal et al. (1997) on low literacy populations. For the FSS, the same blocks were used, where the unshaded block was for the option of “not at all helpful” while the partially shaded block supported the option of “generally helpful” and the fully shaded block was for the option of “extremely helpful”. The PSS, on the other hand, contained a scale of agreement responses, which were visually supported using PCS symbols. Two thumbs down were used for “strongly disagree” and two thumbs up supported the option of “strongly agree”.

**Table 3.4: Graphic Symbols Used for the Likert Scale of Each Measure**

Likert scales of each measure supported with graphic symbols					
<b>PWBI</b>	 You never felt like this	 You felt this once in a while	 You sometimes felt this	 You often felt this	
<b>SFS</b>	 You never need this help	 You need this help once in a while	 You sometimes need this help	 You need this help often	
<b>FSS</b>	Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful
<b>PSS</b>	 Strongly disagree	 Disagree	 Undecided	 Agree	 Strongly agree

Adaptations were finally carried out on the level of the administration of the measures, which were changed from a self-report to a structured interview format. This adaptation was made to accommodate for the low levels of literacy of the participants (Stewart et al., 2012). The instructions, item and available Likert scale response of each measure were read to the participant, after which they pointed to the Likert scale graphic symbol they identified with as

their response instead of having to write their response. The presence of text as well as the graphic symbols provided the necessary support for the participant by reducing the auditory and memory strain which they might have experienced without these forms of visual support (Stewart et al., 2012). Therefore, the participants were able to see and hear the items and scale options and respond by pointing to their answer (Cremers et al., 2015).

### **3.4. Summary**

This chapter provided details regarding the procedure of selecting the measures for the study through systematic searches. The content and context modifications to the four measures, guided by the framework of Stewart et al. (2012), were described. The translation process using Brislin's (1986) framework of the survey materials was explained. Following this, information was provided regarding the selection process of the graphic symbols to be used as visual support for each item of the measures and the validity procedures for the selection of the graphic symbols. Further information was provided regarding the graphic symbols used for the response of the Likert scales of each measure and finally the adaptation which was carried out in terms of the administration of the measures.



## Chapter 4: Methodology

### 4.1. Introduction

This chapter discusses Phase 3 of the methodology of the study, which includes the main aim, sub-aims, the hypotheses and research design of the research. The recruitment of participants is discussed, followed by a description of the sites of recruitment. Next, the sampling method, participant selection criteria and the description of the participants who took part in the study are provided. Details regarding the participants in two pilot studies are described and the outcomes of the pilot studies are then discussed. The ethical considerations regarding the study as well as the materials used for the recruitment of the participants and the materials used for the data collection procedures are described. The chapter also provides a description regarding the research assistants and the procedures for the data collection. Finally, the chapter concludes with the procedures followed in the data preparation, the statistical data analysis methods used and an explanation of how the reliability to the procedures was established.

### 4.2. Research Aim

The main aim of the current study was to explore the relationship between the constructs of perceived social support, stress and well-being of grandparents raising a grandchild with a congenital disability in the Western Cape. To answer the main aim, the following sub-aims were delineated.

#### 4.2.1. Sub-aims

- i. To describe and analyse the relationship between perceived social support and stress.
- ii. To describe and analyse the relationship between perceived social support and grandparent well-being.
- iii. To describe and analyse the relationship between stress and well-being.
- iv. To describe and analyse type of effect (mediating or moderating) of perceived social support on the relationship between stress and grandparent well-being.

- v. To describe and analyse the relationship between the three constructs (stress, well-being and perceived social support) and the reported age, their monthly household income and their perceptions of their financial status of the parenting grandparent.

Based on the findings of the literature reviewed in Chapter 2, it was hypothesised that:

- i. There will be an inverse relationship between perceived social support and the stress of the grandparent, that is, the greater the perceived social support, the lower the levels of stress.
- ii. There will be a positive relationship between perceived social support and the well-being of the grandparent, where the higher the perceived social support, the higher the well-being of the grandparent.
- iii. There will be an inverse relationship between stress and the well-being of the grandparent, where the higher the stress, the lower the well-being of the grandparents.
- iv. Perceived social support will have a mediating effect on the relationship between stress and well-being of the grandparents.
- v. Perceived social support will have a moderating effect on the relationship between stress and well-being of the grandparents.
- vi. The type of grandparent, their age, their monthly household income and their perceptions of their financial status will have an effect on the grandparent's stress, well-being and perceived social support.

### **4.3. Research Design**

An adapted survey design was used for the current study (Lederer et al., 2014; Stewart et al., 2012). Structured one-on-one interviews were conducted. The survey was adapted in terms of the administration and response method. The structured interviews were conducted in the grandparents' language of preference; that is, in the three most common languages in the Western Cape, namely IsiXhosa, Afrikaans or English (Sweetnam Evans, 2015). The researcher who is not proficient in IsiXhosa and Afrikaans, required the assistance of research assistants to

conduct the structured interviews. One research assistant was assigned to the IsiXhosa interviews and another to the Afrikaans and English interviews. For each structured interview, one research assistant and the researcher were present in the interview with the participant (see Figure 4.3 for seating arrangement). The research assistant had the central role of conducting the structured interview with the participant, while the researcher had the role of marking the responses of the participant. The research assistant read the each question aloud to the participant, who then selected and pointed to the graphic symbol as their response rather than writing their choice on the questionnaire. This strategy allowed the participants to identify, select and express their choice of response (Murphy, Tester, Hubbard, Downs, & Macdonald, 2005) even if they had low levels of literacy.

The disadvantage of using a survey design was that a survey usually requires a large number of participants to allow for quantitative analyses (Brancato et al., 2006). The process of using one-on-one interviews was also more time-consuming, with each interview lasting for more than an hour, and was also costly in terms of travelling to the participants' homes (Kelley, Clark, Brown, & Sitzia, 2003). This resulted in a smaller number of participants than expected for a survey design. However, with this face-to-face survey design (Lederer et al., 2014), it was ensured that all the structured interviews were administered the same way (Collins, 2003). There was also less risk of missing data because the researcher marked the responses as soon as the participant voiced or pointed to their selection, which meant that there was a high response (Kelley et al., 2003). There was also better quality of interaction because the researcher and research assistant were able to observe the behaviour of the grandparents during the interview to respectfully and culturally consider their needs during the interview (Elmir, Jackson, & Wilkes, 2011).

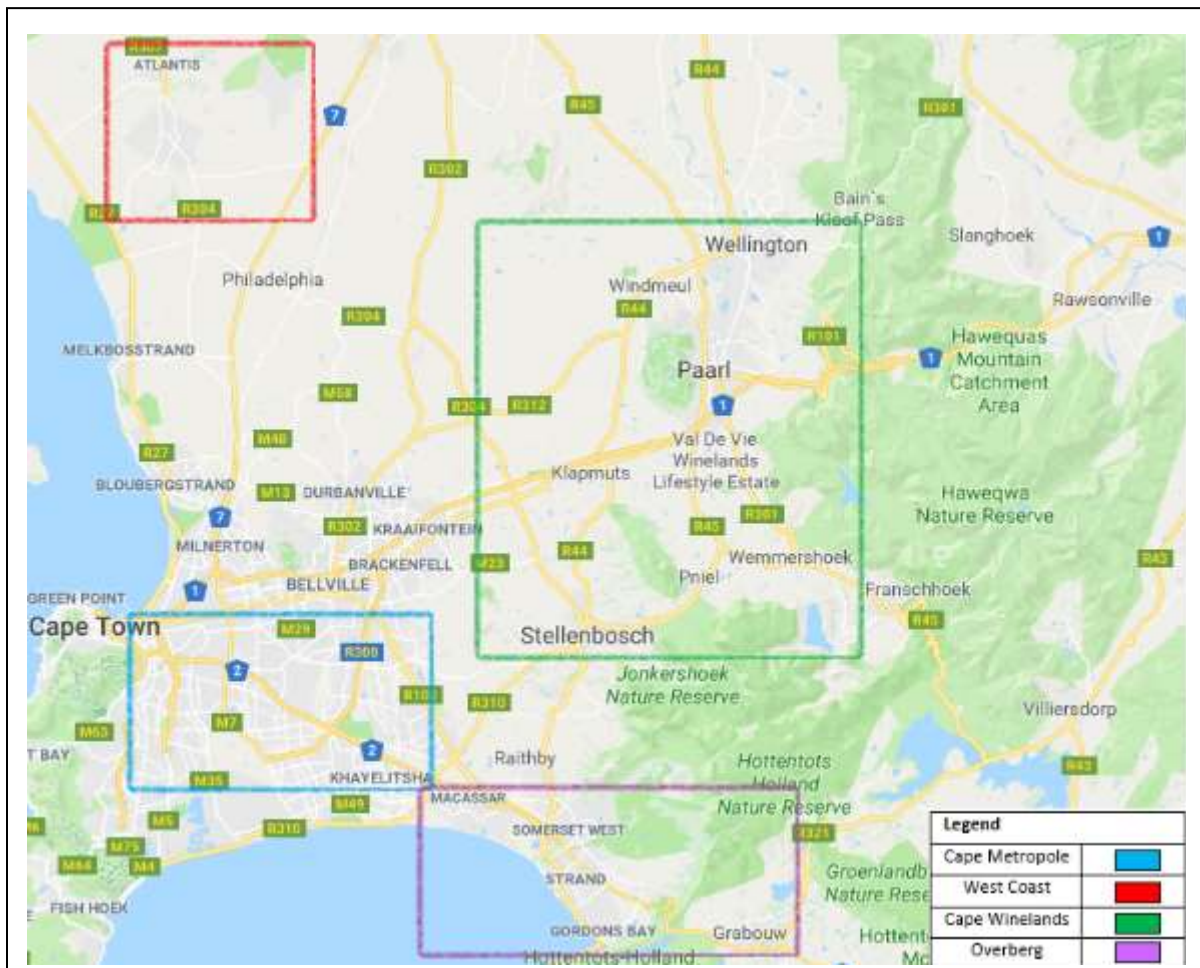
#### **4.4. Participant Recruitment**

This section describes the participants' sites of recruitment, the sampling method, the participant selection criteria and the participant description.

##### **4.4.1. Sites of recruitment.**

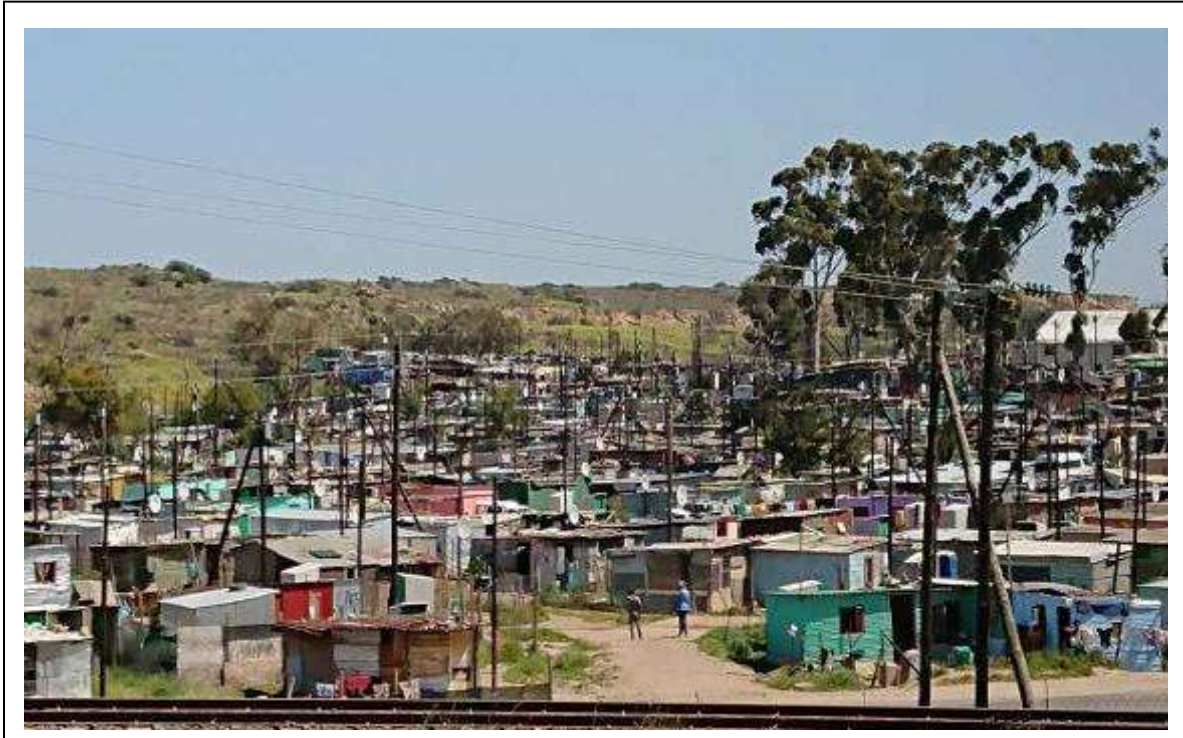
The current study took place in the Western Cape Province of South Africa, as this was the province in which the researcher resided and was therefore more familiar with the area. There is currently no evidence in the literature that the Western Province holds more grandparents raising

a grandchild with a disability than any other province in South Africa. Four main areas of the Western Cape Province were covered, namely the Cape Metropole, Overberg, Cape Winelands and the West Coast region, as illustrated in Figure 4.1. The decision to cover these areas was reliant upon the location of the Special Needs Care Centres and the various Non-Governmental Organisations (NGOs) which serviced these areas (Lederer et al., 2014). These various sites of recruitment were included in the study to reduce any possibility of sampling bias of grandparent caregivers (Lederer et al., 2014). According to the statistical report on poverty trends in South Africa (Lehohla, 2014), it is estimated that 36.9% of the Western Cape's population live in poverty.



**Figure 4.1: Areas of Data Collection in the Western Cape**

Most (80%) of the parenting grandparents who participated in the study lived in over-populated informal settlements. Here, houses were constructed out of corrugated iron sheets and with poor sanitation and water facilities. To illustrate an informal settlement, Figure 4.2 is a photograph taken by the researcher of the Klipheuwel informal settlement.



**Figure 4.2: Example of an Informal Settlement (Klipheuwel)**

The recruitment of participants was carried out at various independent NGOs and independent registered care centres that provide services within the community to families of children with a disability. The Western Cape Department of Social Development as well as the Western Cape Forum for Intellectual Disabilities provided a database of the various registered NGOs and care centres. To ensure that the NGOs correlated with those which are currently open and functioning, the researcher further liaised with multidisciplinary teams who worked with Children with Severe and Profound Intellectual Disability (CSPID) at the various day-care centres in the Western Cape. By liaising with the CSPID teams, it was possible to ensure that the various registered centres were accessible. It was also a means of confirming the contact details of current centre managers since some of the information in the databases was outdated. Consequently, 36 NGOs were contacted via email or through visits if no reply was obtained from

the email. A significant amount of time was dedicated to establishing rapport with each of the centre managers, both via email and in person, where the goals of the study were clearly communicated as well as what would be expected from the organisation and participants. It was also important to communicate that the correct ethical procedures were being undertaken by the researcher before data collection could begin. From the 36 NGOs, a total of 16 NGOs were willing to participate and were able to provide a list of possible participants for the study. The 20 NGOs that did not participate in the study either did not have participants who met the selection criteria (17 NGOs) or were not available to assist (3 NGOs). Further recruitment was also carried out via informal networks, such as contacts within the communities, with people who knew of grandparent caregivers, or via social workers who knew of grandparents raising their grandchild with a congenital disability in their community.

The managers of the NGOs provided the contact details, telephone numbers and addresses of each participant. For many of the participants, establishing contact via telephone was challenging as their numbers were either invalid or not in use. Therefore, the researcher and assistant travelled to each participant's house. For some areas of the Western Cape, namely the informal settlements, it was important to have a contact person known to the community, that is, a liaison, who would provide guidance on where to find the participant's house. A considerable amount of time was spent travelling between interviews to find each participant's house as, in most cases, there were no clear indications of house numbers or street names in the informal settlements. In some cases, the help of local community residents was sought to direct the researcher and assistant to the correct location of the grandparents' home. For those grandparents who lived in areas where gang violence prevailed, the community liaison arranged for the grandparents to attend their interview at the NGO or care centre attended by their grandchild.

Within the informal settlements, the NGOs were usually founded in the homes of the managers, where the lack of physical space for the children as well as the shortage of resources was visible, together with the great need for such services within these communities. For the grandparent caregivers, the lack of resources and the financial constraints were evident, where many of the grandparents who took part in the study within the informal settlements had a house that was made of corrugated iron. Most of the homes had many other relatives and other children living in

the same household and the grandparent caregiver often shared a room with a number of other relatives or other children. Furthermore, the lack of sanitation was visible; most households shared one toilet with a number of other neighbours, which poses yet another challenge that a grandparent raising a grandchild with a disability has to overcome.

#### 4.4.2. Sampling

Purposive sampling was used to recruit the participants for the study according to their availability, as outlined in Table 4.3. The disadvantage of using this method of sampling is the poor generalisability of the results of the study, which would be limited to the characteristics of the participants (Bradshaw, Atkinson, & Doody, 2017). By using various sites of participant recruitment, namely from NGOs, special needs care centres and informal networks, there was a greater chance of reducing selection bias. Therefore, all types of grandparent caregivers raising their grandchild with a congenital disability were included. The 16 NGOs who agreed to participate in the study identified 81 potential participants. Of the 81 identified participants, 10 did not meet the selection criteria due to their grandchild being older than 9 years, 11 were uncontactable, 3 were outside of focus area, and 7 did not consent to participate. As a result, 50 participants were identified who were willing to take part in the study.

#### 4.4.3. Participant selection criteria.

Table 4.1 outlines the selection criteria for the participants.

**Table 4.1: Participant Selection Criteria**

<b>Criteria</b>	<b>Rationale</b>	<b>Measure</b>
Participant should be a grandparent	Grandparenting is determined by the generational link within the family and is not according to the age of the grandparent, as South African-based studies (Samuels, 2013) identify the age of co-parenting grandparents being between the ages of 36 and 65 years. Linking this information with international studies (Kropf & Kolomer, 2004), the age of the grandparent is suspected to be from the age of 35 years and above.	Biographical information
Grandparents should be the sole parents or co-parents	In South Africa, grandparents are either sole parents where they raise the grandchild in the absence of the parent of the grandchild (Statistics South Africa & Leholo, 2014a) or co-	Biographical information

Criteria	Rationale	Measure
	<p>parents with at least one parent of their grandchild (Samuels, 2013). In both cases, the parent of the grandchild may be absent for long periods of time and/or present for only short periods (Cunningham, Elo, Herbst, &amp; Hosegood, 2010). Parenting grandparents partake in parenting routines and parenting styles while carrying out daily caregiving activities for their grandchild. Activities which qualify as care and full-time caregiving comprise daily activities such as food preparation for the household, washing and bathing, helping with school homework, attending medical and school appointments with the grandchild and ensuring that the grandchild has access to appropriate healthcare activities such as provision of medication and treatment of injuries (Hanass-Hancock &amp; Casale, 2014).</p>	
Grandchild has a congenital disability	Having a grandchild with a congenital disability infers that the grandchild would generally already have a diagnosis due to early identification of the disability by the paediatrician or medical practitioner (Watson, 2008).	Biographical information
Grandparent of a grandchild with a diagnosed congenital disability from birth to the age of 9 years who is not attending school	According to the education constitution, all children should be in a formal schooling system by the age of 6 years (Samuels, Slemming, & Balton, 2012). However, children who have a disability often experience difficulty being placed in schools due to the poor availability of special needs education in their community (Hanass-Hancock et al., 2013). These children would be either attending a crèche or day-care centre or be kept at home (DSD, DWCPD, & UNICEF, 2012). Keeping to the age of early childhood development, which ranges from the age of 0–7 years in South Africa (Samuels, Slemming, & Balton, 2012), the current study therefore considered grandchildren up to the age of 9 years who were not attending school.	Biographical information
Grandparent should be fluent in either English, Afrikaans or isiXhosa	Semi-structured interviews require the grandparent to be fluent in the language they are most comfortable with to encourage them to freely express themselves. However, it is important to also consider languages which are most relevant to the location in which the study is due to take place. The three main languages which are the most applicable to the context of the current study based in the Western Cape (Sweetnam Evans, 2015) are English, Afrikaans and isiXhosa. Therefore, the materials and interviews were available to the grandparents in either of these three languages. English, isiXhosa and Afrikaans were selected for the current study due to their high prevalence in the province of the Western Cape, where 20.30% of the population speak English, 24.70% speak isiXhosa and 49.70% speak Afrikaans (Sweetnam Evans, 2015).	Language preference and fluency were identified through biographical information.
Grandparent should live within the Western Cape	The region of the Western Cape provided a range of locations where grandparents would be present. This area was chosen because the researcher lives and knows the areas of the Western Cape.	Biographical information; participant information from NGO



**4.4.4. Participant description.**

A total of 50 parenting grandparents from the Cape Metropole area participated in this study. The participants were from the areas of Delft (n = 2), Ottery (n = 2), Lotus River (n = 1), Eerste River (n = 1), Mitchells Plain (n = 4), Kew Town (n = 1), Nyanga (n = 2), Imizamo Yethu (n = 2), Mfuleni (n = 4), Gugulethu (n = 3), Langa (n = 1), Khuyasa (n = 1), Samora Machel (n = 3), Khayelitsha (n = 8) and Phillipi (n = 3). Participants also originated from the Cape Winelands area specific to Mbekweni (n = 4), and from the West Coast region specific to Atlantis (n = 3) as well as the Overberg region area specific to Macassar (n = 1), Strand (n = 1), Broadlands (n = 1) and Grabouw (n = 4) (situated in the Overberg region). Table 4.2 outlines the description of the participants.

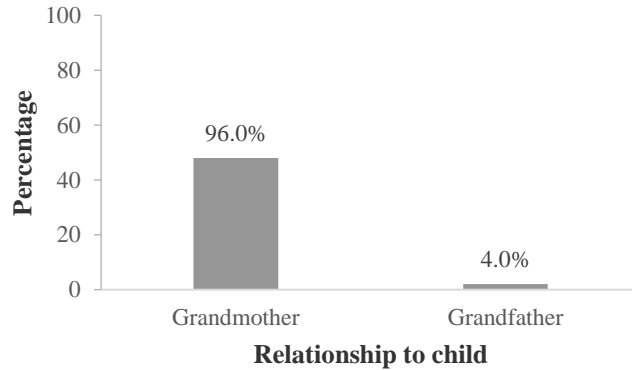
**Table 4.2: Biographical Description of Grandparent Caregivers (N = 50)**

Biographical description	Results												
<p><b>Age (years) of grandparents</b>                      The grandparents varied in age from 39 years to 74 years, with a mean age of 55.06 (S.D = 8.70) years, where:                      4.% (2) were between 31–40 years of age,                      24% (12) were between 41–50 years of age,                      44% (22) were between 51–60 years of age                      24% (12) were between 61–70 years of age, and                      4% (2) were between 71–80 years of age.</p>	<table border="1"> <caption>Age of grandparent caregiver</caption> <thead> <tr> <th>Age Group</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>31-40</td> <td>4.0%</td> </tr> <tr> <td>41-50</td> <td>24.0%</td> </tr> <tr> <td>51-60</td> <td>44.0%</td> </tr> <tr> <td>61-70</td> <td>24.0%</td> </tr> <tr> <td>71-80</td> <td>4.0%</td> </tr> </tbody> </table>	Age Group	Percentage	31-40	4.0%	41-50	24.0%	51-60	44.0%	61-70	24.0%	71-80	4.0%
Age Group	Percentage												
31-40	4.0%												
41-50	24.0%												
51-60	44.0%												
61-70	24.0%												
71-80	4.0%												
<p><b>First language of grandparent caregivers</b>                      Of the 50 grandparents, 62% (31) were IsiXhosa speaking, 32% (16) were Afrikaans speaking and 6% (3) were English speaking.</p>	<table border="1"> <caption>First language of grandparent caregivers</caption> <thead> <tr> <th>Language</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>isiXhosa</td> <td>62.0%</td> </tr> <tr> <td>Afrikaans</td> <td>32.0%</td> </tr> <tr> <td>English</td> <td>6.0%</td> </tr> </tbody> </table>	Language	Percentage	isiXhosa	62.0%	Afrikaans	32.0%	English	6.0%				
Language	Percentage												
isiXhosa	62.0%												
Afrikaans	32.0%												
English	6.0%												

**Biographical description**

**Relationship to child with a disability**

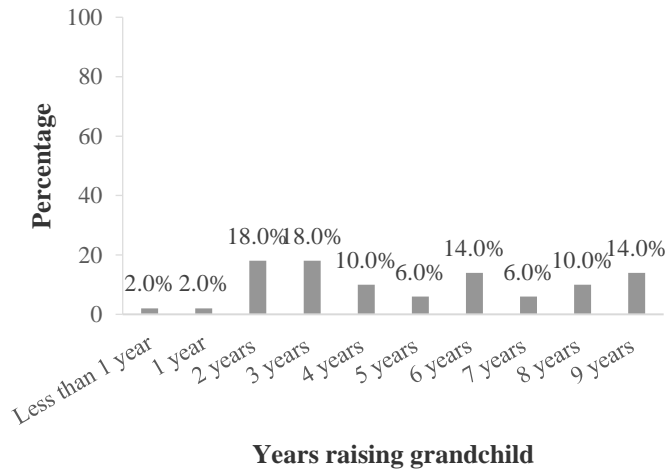
From the 50 grandparents who were raising a child with a disability, 96% (48) were grandmothers and 4% (2) were grandfathers.



**Years raising grandchild**

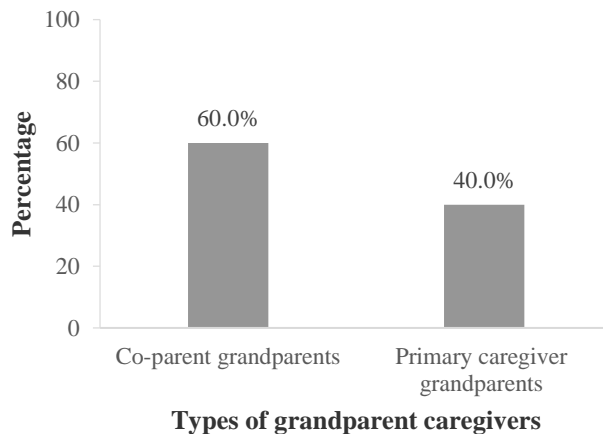
The number of years during which the grandparents reported to have been raising their grandchild varied from 3 months to 9 years ( $M = 4.95$ ,  $SD = 2.62$ ), where:

2% (1) had been raising their grandchild for 3 months,  
 2% (1) had been raising their grandchild for 1 year,  
 18% (9) had been raising their grandchild for 2 years,  
 18% (9) had been raising their grandchild for 3 years,  
 10% (5) had been raising their grandchild for 4 years,  
 6% (3) had been raising their grandchild for 5 years,  
 14% (7) had been raising their grandchild for 6 years,  
 6% (3) had been raising their grandchild for 7 years,  
 10% (5) had been raising their grandchild for 8 years,  
 and  
 14% (7) had been raising their grandchild for 9 years.



**Type of grandparent**

Of the 50 grandparent caregivers, 60% (30) were co-parenting with at least one parent of their grandchild, and 40% (20) were primary caregivers in the absence of the parent of the grandchild.

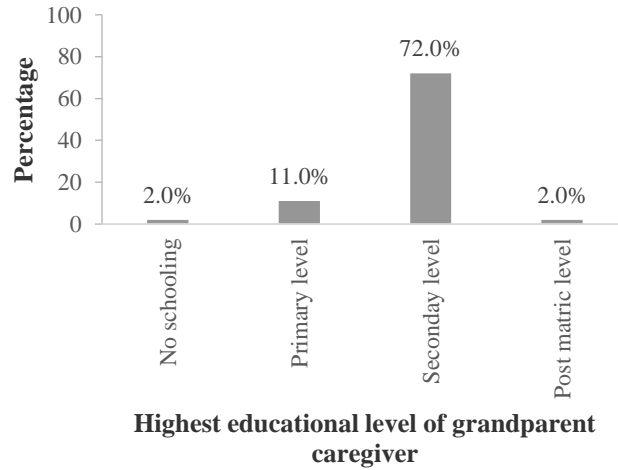


## Biographical description

### Education level of grandparents

The grandparents had a range of highest levels of education, where:

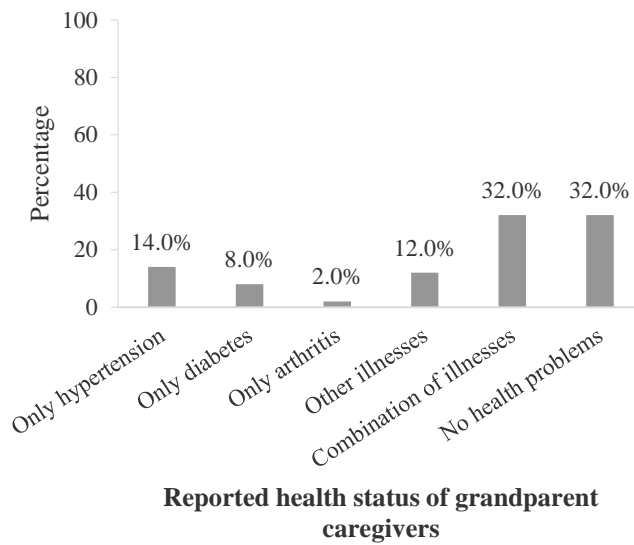
2% (1) had no form of schooling,  
72% (36) had secondary level education,  
22% (11) had primary level education, and  
4% (2) had post-matric education.



### Medical health problems of grandparents

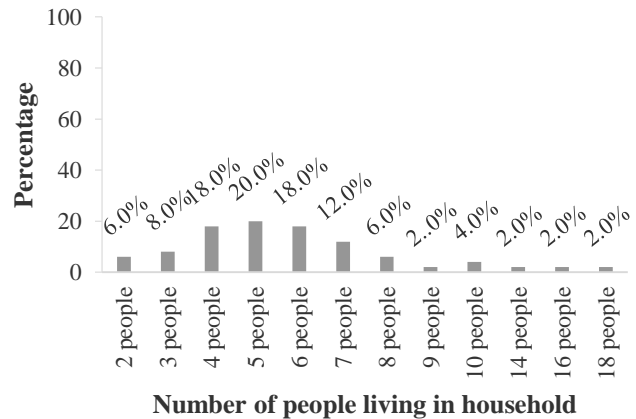
Of the 50 grandparents, 32% (16) had no health problems, while 68% (34) reported a medical condition, where:

14% (7) had hypertension,  
8% (4) had diabetes,  
2% (1) had arthritis and  
12% (6) had other health problems, namely, HIV (2), ulcers (2), cardiac problems and osteo-fibrosis (1), or did not divulge (1),  
32% (16) had combinations of illnesses, such as  
diabetes, hypertension, arthritis and other (asthma) (1),  
diabetes and hypertension (1),  
diabetes and arthritis (3),  
hypertension and arthritis (4),  
diabetes, hypertension and arthritis (2),  
diabetes, hypertension and other (thyroidism) (1),  
diabetes, hypertension and other (asthma) (2),  
diabetes, arthritis and other (asthma) (1), and  
hypertension, arthritis and other (disclosed HIV) (1).

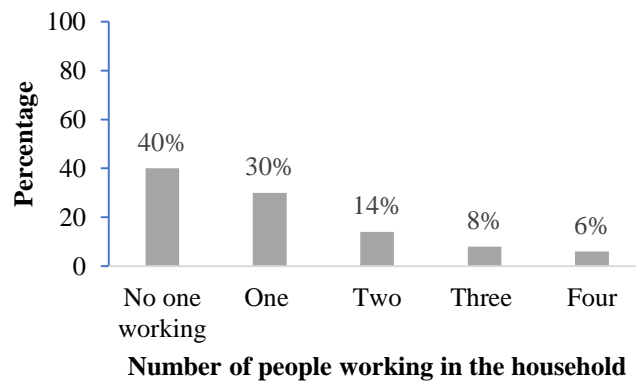


**Biographical description****Results****Number of people in household**

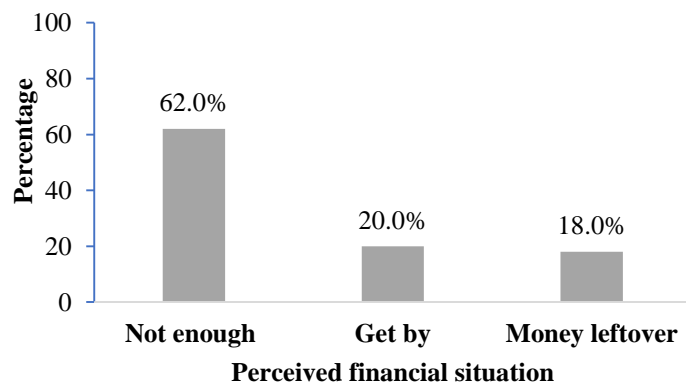
The number of people in the household ranged from a minimum of 2 people to a maximum of 18 people ( $M = 6.02$ ,  $S.D = 3.18$ ), where 6% (3) had 2 people, 8% (4) had 3 people, 18% (9) had 4 people, 20% (10) had 5 people, 18% (9) had 6 people, 12% (6) had 7 people, 6% (3) had 8 people, 2% (1) had 9 people, 4% (2) had 10 people, 2% (1) had 14 people, 2% (1) had 16 people, and 2% (1) had 18 people in the household.

**Number of people working and contributing to households**

Of the 50 grandparents, 42% (21) had no one in the household who worked, 30% (15) had one person in their household who worked, 14% (7) had two people working, 8% (4) had three people who worked, and 6% (3) had 4 people who worked in their household.

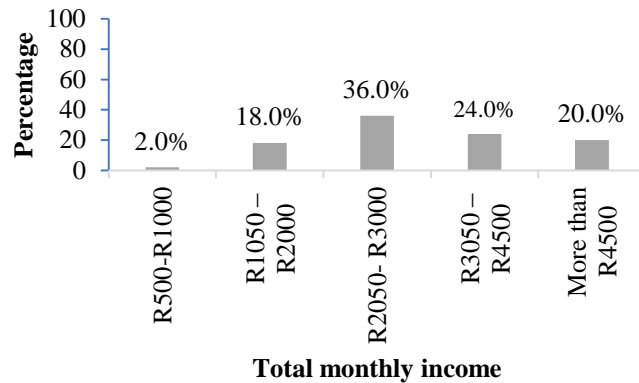
**Perceived financial situation**

The majority, 62% (31) of the 50 grandparents, viewed their household income as being “not enough”, while 20% (10) reported to “get by” every month and only 18% (9) reported to have some money left at the end of the month.

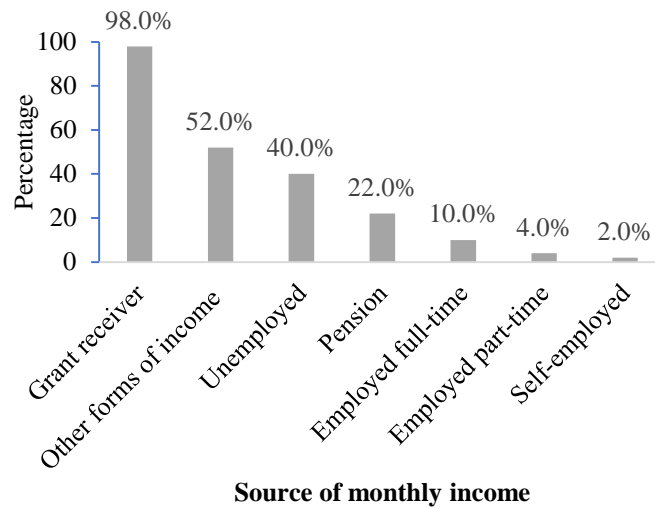


**Biographical description****Total monthly income**

From the 50 grandparents, 36% (18) had a household monthly income of R2050–R3000, while 24% (12) had a household income of R3050–R4500 and 20% (10) had a monthly income of more than R4500. On the other hand, 18% (9) had a low household income of R1050–R2000 and one grandparent had the lowest household income of R500–R1000.

**Source of monthly household income**

Of the 50 grandparents, 98% (49) accessed their social grants. In terms of the other sources of their household income in combination: 52% (26) relied on other forms of income, including money from their children, 40% (20) were unemployed, 22% (11) relied on their pension, 10% (5) were full-time employed, 4% (2) were employed part-time, and 2% (1) was self-employed. None of the grandparents were retired.



From the biographical information form, grandparents were asked about the reasons for raising their grandchild. The sole-parenting grandparents reported to be raising their grandchild alone as the child's biological parents were not involved ( $n = 20$ ; 40%), the mother did not want the grandchild and abandoned the child ( $n = 8$ ; 16%), the mother had passed on ( $n = 4$ ; 8%), the parents had a substance abuse problem ( $n = 3$ ; 6%), the mother was working and living elsewhere ( $n = 3$ ; 6%), the grandchild was being neglected by the parents ( $n = 1$ ; 2%), or the parent was finishing school elsewhere in South Africa ( $n = 1$ ; 2%). In the case of co-parenting grandparents ( $n = 30$ ; 60%), they reported raising their grandchild because they were either supporting the mother of the grandchild who lived in the same household ( $n = 18$ ; 36%) or they were supporting both parents of the grandchild, who were living in the same household ( $n = 5$ ;

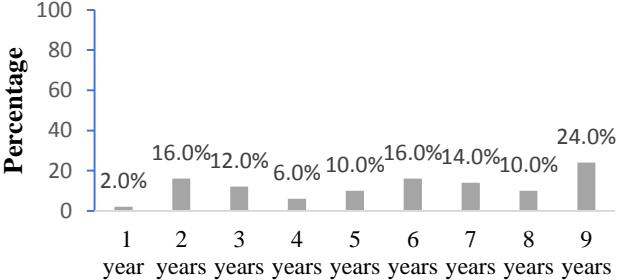
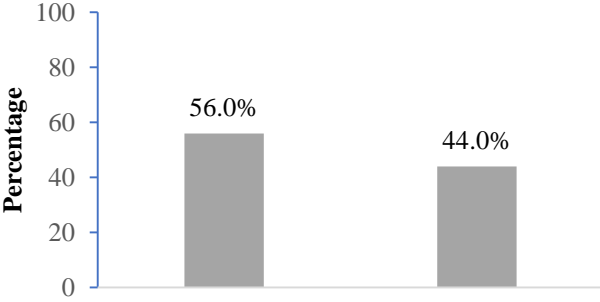
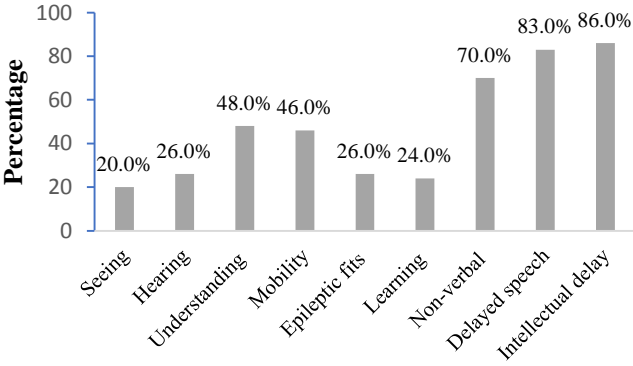
10%). Other co-parenting grandparents reported that they were supporting the mother of the grandchild because she was still in school while living in the same household (n = 3; 6%) or because the mother of the child was working full-time while living in the same household (n = 4; 8%).

The number of people living in the household ranged from 2 to 8 people. It can be seen that 62% (n = 31) of the grandparents perceived that they were struggling financially, with a maximum of 36% of grandparents' (n = 18) having a household income of R1050 (\$72) to R2000 (\$138).

Of the 50 grandparents, 98% (n = 49) accessed a monthly social grant. The low levels of unemployment were also highlighted in this data with 60% being unemployed while 18% (n = 9) of grandparent caregivers were full-time employed as char workers (n = 7; 14%), or as a bookkeeper (n = 1; 2%) or a manager in an NGO (n = 1; 2%). Four grandparent caregivers were part-time employed as either casual cleaners (n = 2; 4%), a casual worker in a catering company (n = 1; 2%) or as a seasonal farm worker (n = 1; 2%). Two of the grandparent caregivers were self-employed where they either sold street food (n = 1; 2%) or had their own tuck shop (n = 1; 2%). Out of the 50 grandparents, 98% (n = 49) accessed some form of social grant to run the household, where grants ranged from disability grants for the child to foster carer grants. For those grandparent caregivers who had other sources of income (n = 27; 54%) to run the household, sources included the mother or father of the grandchild who worked and contributed (n = 6; 12%), or their husband/wife/partner who worked and contributed (n = 8; 16%). Other sources of income included other adult children or relatives of the grandparent who worked and contributed to the household (n = 40; 20%) or from their spouse's disability grant or pension.

The descriptions of the grandchildren's information are presented in Table 4.3.

**Table 4.3: Descriptions of Grandchild with a Disability**

Descriptions of grandchild	Results																				
<p><b>Age of grandchild</b>                      The ages of the grandchildren ranged from:                      1 year: 2% (1)                      2 years: 16% (8)                      3 years: 12% (6)                      4 years: 6% (3)                      5 years: 10% (5)                      6 years: 16% (8)                      7 years: 14% (7)                      8 years: 10% (5)                      9 years: 24% (12)</p>	 <p style="text-align: center;"><b>Ages of grandchildren</b></p> <table border="1"> <caption>Data for Ages of grandchildren</caption> <thead> <tr> <th>Age (years)</th> <th>Percentage</th> </tr> </thead> <tbody> <tr><td>1</td><td>2.0%</td></tr> <tr><td>2</td><td>16.0%</td></tr> <tr><td>3</td><td>12.0%</td></tr> <tr><td>4</td><td>6.0%</td></tr> <tr><td>5</td><td>10.0%</td></tr> <tr><td>6</td><td>16.0%</td></tr> <tr><td>7</td><td>14.0%</td></tr> <tr><td>8</td><td>10.0%</td></tr> <tr><td>9</td><td>24.0%</td></tr> </tbody> </table>	Age (years)	Percentage	1	2.0%	2	16.0%	3	12.0%	4	6.0%	5	10.0%	6	16.0%	7	14.0%	8	10.0%	9	24.0%
Age (years)	Percentage																				
1	2.0%																				
2	16.0%																				
3	12.0%																				
4	6.0%																				
5	10.0%																				
6	16.0%																				
7	14.0%																				
8	10.0%																				
9	24.0%																				
<p><b>Gender of grandchild</b>                      The genders of the grandchildren were:                      male: 56% (28)                      female: 44% (22)</p>	 <p style="text-align: center;"><b>Gender of grandchild</b></p> <table border="1"> <caption>Data for Gender of grandchild</caption> <thead> <tr> <th>Gender</th> <th>Percentage</th> </tr> </thead> <tbody> <tr><td>Male</td><td>56.0%</td></tr> <tr><td>Female</td><td>44.0%</td></tr> </tbody> </table>	Gender	Percentage	Male	56.0%	Female	44.0%														
Gender	Percentage																				
Male	56.0%																				
Female	44.0%																				
<p><b>Disability-related characteristics of grandchild</b>                      20% (10) had difficulty seeing                      26% (13) had difficulty hearing                      48% (24) had difficulty understanding                      46% (23) had difficulty walking and moving                      26% (13) had epileptic fits                      24% (12) had difficulty learning                      70% (35) were not able to speak                      83% (34) had different speech from peers of their same age                      18% (9) of children under 2 years could not speak                      89% (45) were unable to name at least one object                      86% (43) were overall mentally delayed</p>	 <p style="text-align: center;"><b>Areas of reported disability of grandchild</b></p> <table border="1"> <caption>Data for Areas of reported disability of grandchild</caption> <thead> <tr> <th>Area of Disability</th> <th>Percentage</th> </tr> </thead> <tbody> <tr><td>Seeing</td><td>20.0%</td></tr> <tr><td>Hearing</td><td>26.0%</td></tr> <tr><td>Understanding</td><td>48.0%</td></tr> <tr><td>Mobility</td><td>46.0%</td></tr> <tr><td>Epileptic fits</td><td>26.0%</td></tr> <tr><td>Learning</td><td>24.0%</td></tr> <tr><td>Non-verbal</td><td>70.0%</td></tr> <tr><td>Delayed speech</td><td>83.0%</td></tr> <tr><td>Intellectual delay</td><td>86.0%</td></tr> </tbody> </table>	Area of Disability	Percentage	Seeing	20.0%	Hearing	26.0%	Understanding	48.0%	Mobility	46.0%	Epileptic fits	26.0%	Learning	24.0%	Non-verbal	70.0%	Delayed speech	83.0%	Intellectual delay	86.0%
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Learning	24.0%																				
Non-verbal	70.0%																				
Delayed speech	83.0%																				
Intellectual delay	86.0%																				

From Table 4.3 it can be seen that the grandchildren were all below the age of 9 years and were mostly male in gender. The disability characteristics of the grandchild was used as the indicator of the disability to overcome the possibility that the grandparent may not know the diagnosed name of the disability. The grandchildren had a number of disability-related characteristics which were in line with the selection criteria for the study.

## **4.5. Pilot Studies**

The pilot study was used to test the procedural script, the instructions to the participants, the procedure for the structured interview and the timing of the semi-structured interview. Any recommended adaptations and changes to the procedures and questionnaires were considered. Two pilot studies were completed. The aims, procedures, results and recommendations are described in Table 4.4 and Table 4.5.

### **4.5.1. Participants of pilot studies**

The pilot study participants met the participant selection criteria of the main study outlined in section 4.4.3. Three participants took part in Pilot Study 1 and Pilot Study 2 had one participant who was raising a grandchild without a disability, to determine the clarity of the visual supports used in the materials.



**Table 4.4: Pilot Study 1 (n = 3)**

Aim	Materials/measures	Procedures	Results	Changes made for main study
To test the clarity of the invitation letter, the consent form and the biographical data form	Invitation letter Consent form Biographical form	The participants were read the invitation form and were asked if they had any questions regarding its content. The participants were read the consent form and they were asked if they required assistance. They were then required to sign the consent form. For the biographical form, each question was read to the participants and they were required to verbally answer the questions. The answers were then filled in by the researcher or the research assistant.	The participants required some explanation regarding the study aim. They agreed to participate in the study and were able to sign the consent form. For the biographical form, a further adaptation of some of the questions was recommended by the research assistant.	Graphical symbols were used as visual support for the invitation letter and the consent form. This also illustrated what was written to ensure that the participants understood the aim of the research and the content of the consent form.
To determine the appropriateness of the Likert scale and their graphic symbols for the measures: <ul style="list-style-type: none"> <li>• Parental Stress Scale (PSS)</li> <li>• Personal Well-Being Index (PWBI)</li> <li>• Support Function Scale (SFS)</li> <li>• Family Support Scale (FSS)</li> </ul>	Likert scales for the: <ul style="list-style-type: none"> <li>• PSS</li> <li>• PWBI</li> <li>• SFS</li> <li>• FSS</li> </ul>	The participants were provided with a brief form containing one example of a question/statement taken from the main questionnaires together with its Likert scale illustrations. The label for each of the scale levels was not provided so as to test the understandability of the illustrations.	The participants were able to understand the illustration and were able to indicate their choice of response on the illustrated Likert scale.	It was recommended that the extreme positive be used instead as: PWBI – “quite often” SFS – “quite often” FSS – “extremely helpful” The Likert scales for the PWBI, SFS and FSS were therefore reduced from a 5-point scale to a 4-point scale to reduce the complexity and slight semantic variation (Sousa & Rojjanasrirat, 2010).

Aim	Materials/measures	Procedures	Results	Changes made for main study
To determine the clarity of the instructions of the questionnaires	Instructions for the: <ul style="list-style-type: none"> <li>• PSS</li> <li>• PWBI</li> <li>• SFS</li> <li>• FSS</li> </ul>	The participants were read the instructions and were then asked to indicate verbally whether they understood the instructions.	The participants indicated that they understood the instructions. However, they were unwilling to mark their own response forms and instead requested that the research assistant write in their responses for them.	Because the participants were reluctant to fill in their own questionnaire and low levels of literacy, it was clear that changes had to be made in terms of the instructions and the method of response for each question/statement of the measures. A more visual layout was adopted specifically to the principles of the Talking Mats™ framework. The written instructions for each measure were therefore verbally presented to the participants and changed to include instructions on how to answer each question/statement using the principles of the Talking Mats™ (Murphy et al., 2005).
To determine the understandability and difficulty of the items in measures	<ul style="list-style-type: none"> <li>• PSS</li> <li>• PWBI</li> <li>• SFS</li> <li>• FSS</li> </ul>	For each of the questionnaire items, the participants were asked to mark in the relevant column whether they understood each question/statement of the four measures. After completion of the questionnaires, the respondents were asked, “How difficult or easy was it to answer the questions?” (D. Collins, 2003).	The participants opted to not mark their own questionnaires and instead requested for the assistant to do this for them. The participants verbally indicated whether or not they understood the questions. The participants indicated that they easily understood the items. The participants differed in their opinion of the level of difficulty of the questionnaires. This was due to the amount of auditory information they were required to retain because they could not read the questions/items for themselves. This indicated that the original written questionnaire format would prove to be difficult for the main data collection.	No changes were made to the items. To reduce the possibility of auditory overload for the participants, the response method was adapted using the principles of the Talking Mats™ framework where graphic symbols accompanied the verbal information (Murphy et al., 2005).

Aim	Materials/measures	Procedures	Results	Changes made for main study
To determine the feasibility of carrying out group sessions for data collection		The participants were asked whether they were comfortable to fill in the questionnaires as a group.	The participants were not comfortable to answer their questions in the presence of another participant.	A one-on-one interview approach was therefore adopted for the main data collection procedure.
To determine the feasibility of participant recruitment at the NGOs	Selection criteria (see Table 3.6.1)	A discussion with the managers of the NGOs took place prior to the pilot date. Logistical issues were discussed specific to: - the identification of participants according to selection criteria - the time at which the interviews would take place - the space available to carry out the interviews.	The manager of the NGO is a valuable source for identifying potential participants and to facilitate this process, they required a reminder of the selection criteria for the participants needed for the study. The NGO where this first round of the pilot study was conducted offered to bring the participants to the NGO. This was not be a sustainable method of accessing participants because each NGO is different in terms of their financial and logistical commitments.	Logistical issues were differently managed at each NGO and were discussed with the manager of each NGO. As a means of ensuring that the participants were correctly selected, a brief checklist with the selection criteria of the participants was provided to the managers. Further discussion topics prior to data collection included: - Access the participants - Facility or room available to interview the participants - An outline of the procedures which will be followed - A list of services available at the NGOs within the community for the participants to access. This was part of the community mapping process in providing the participants with available social networks within their community.
To determine the reliability of the procedural script for the semi-structured interview by the research assistant	Digital Olympus Voice recorder, procedural script and checklist	The assistant was recorded while reading the procedural script. Two raters were required to listen to the recording and to use the checklist to determine whether the procedural script was adhered to and reliable.	The procedural script was well adhered to.	Changes were made to the procedural script in terms of the procedure of the survey.

Aim	Materials/measures	Procedures	Results	Changes made for main study
To determine the adequacy of the audio recordings regarding sound quality for procedural integrity	Digital recorder and questionnaire pack	The digital recorder was switched on at the beginning of the pilot study. The procedural script which was used by the assistant was recorded. The recording was listened to by two raters to determine whether the sound quality was appropriate.	The sound quality of the recording was appropriate.	Because the procedure of the response method was changed from written to visual (graphic symbols) using the principles of the Talking Mats™ framework, a video recording would be considered instead.

#### *4.5.1.1 Pilot Study 1*

The Pilot Study 1 provided a number of recommendations. The recruitment of the participants was refined through the use of a selection criteria checklist. The researcher provided the checklist to the managers of the NGOs to ensure that the possible identified participants met the selection criteria. Graphic symbols had to be added to both the invitation letter and the consent forms to increase the clarity of the aims of the study and the contents of the consent form for all the participants. For all four measures, namely the PSS, the PWBI, the SFS and the FSS, the instructions were to be modified from a written response method to a verbal response method (Stewart et al., 2012).

Furthermore, the method of administration of the measures for the participants was to be changed from a written format to a verbal and visually supported structured interview. The Talking Mats™ framework was considered, where the instructions and items for each measure would be presented verbally to the participant using graphic symbols. The participant would then be required to respond by putting the graphic symbol under the corresponding Likert scale graphic symbol to which they related (Murphy et al., 2005). The structure of the Likert scales was to be changed to reduce its complexity and the length of the scale. For example, a 5-point was changed to a 4-point scale. Reducing the Likert scale responses also reduced the level of complexity of the translations from English to IsiXhosa (Sousa & Rojjanasrirat, 2010).

The procedures were modified so that each participant would be seen in a one-on-one interview format instead of a group session. The recording of each session was to be changed from an audio recording to a video recording for the responses of the participants on the Talking Mats™ framework. A second pilot study was carried out to test the recommendations from Pilot Study 1. The details pertaining to Pilot Study 2 are described in Table 4.5.

**Table 4.5: Pilot Study 2 (n = 1)**

Aim	Materials	Procedures	Results	Recommendations
To determine the clarity of the procedural script and the flow of the survey with the research assistant for all three languages (English, Afrikaans and isiXhosa)	Procedural script and measures: <ul style="list-style-type: none"> <li>• PSS</li> <li>• PWBI</li> <li>• SFS</li> <li>• FSS</li> </ul>	Prior to the pilot, the research assistant was required to read through the procedural script and to express whether it was clear and whether the sequence of the semi-structured interview was understandable in all three languages.	The assistant understood the procedure and the content of the procedural script. She was also able to understand the sequence of the semi-structured interview. However, at the beginning of the session, the assistant was focused more on reading the procedural script to the participant rather than translating to the participant. As the session progressed, this changed and she became more relaxed and engaged better with the participant while translating for the researcher. After the session, time was taken to discuss the importance of listening, engaging and acknowledging the grandparent's responses. It was also explained to the assistant also explained that the parts where she had to read from the procedural script were specifically for the instructions and the statements/questions of the measures so that there was consistency in how these were presented to all the participants in the main study.	Several practice sessions were held until the assistant was able to perform this goal confidently and consistently. However, to enable the display of the graphic symbol cards and the reading of the questions by the assistant, a standing flip-booklet was devised.
To determine the clarity of the invitation letter containing graphic symbols	Invitation letter containing graphic symbols	The invitation letter containing graphic symbols was explained and read to the participant according to the procedural script. The participant was asked to indicate at any point if they did not understand the information.	The participant was able to understand the content of the invitation letter containing illustrations.	No changes were made.
To determine the clarity of the consent form containing graphic symbols	Consent form containing graphic symbols	The consent form containing graphic symbols was explained to the participants according to	The participant was able to understand the content of the illustrated consent form, and after each item was read to her, the	

Aim	Materials	Procedures	Results	Recommendations
		the procedural script and read to the participant. After each item in the consent form was read to the participant, they were requested to indicate whether or not they agreed to the terms of the study.	participant was able to select the appropriate choices to accept to participate in the study.	No changes were made.
To determine the clarity of the revised instructions for the procedure of the survey	Procedural script containing the instructions for the: <ul style="list-style-type: none"> <li>• PSS</li> <li>• PWBI</li> <li>• SFS</li> <li>• FSS</li> </ul>	The procedural script was used to inform the participants what they were expected to do.	The assistant read the instructions for the measure from the procedural script. The participant expressed that she understood what was expected of them.	No changes were made.
To test the suitability of the Likert scale from 5 to 4 responses for the FSS, SFS and the PWBI	Original Likert scales with the adapted Likert scales of the: <ul style="list-style-type: none"> <li>• PSS</li> <li>• PWBI</li> <li>• SFS</li> <li>• FSS</li> </ul>	The participant was required to answer an example of the item of the PWBI, SFS and FSS using the 4-point Likert scale. The participant was asked if they understood the labels for the 4-point scale.	The participant was able to easily answer the items on the 4-point scale.	No changes were made.
To train the research assistants to fidelity of 100% to carry out the interview according to the procedural script and checklist	Materials	The two research assistants were trained on separate occasions. They were provided with the interview material and the interview schedule and checklist to familiarise themselves and to practise the interview procedures on two different occasions.	During the practice sessions, the research assistants were able to carry out the interview from 60% to 80% to 100% fidelity. The translated materials were helpful in reducing the anxiety experienced by the research assistants due to lesser amount of information they had to remember. The research assistants could also focus on creating a natural process of the interview	No changes were made.

Aim	Materials	Procedures	Results	Recommendations
<p>To test the procedure for the survey using the graphic symbols together with the read items of each measure in a Talking Mats™ framework</p>	<p>Questionnaires containing graphic symbols:</p> <ul style="list-style-type: none"> <li>• PSS</li> <li>• PWBI</li> <li>• SFS</li> <li>• FSS</li> </ul>	<p>Each statement was read aloud, after which a graphic symbol card representing the core concept of the statement was provided to the participant. The graphic symbols of the Likert scales for the relevant measure were displayed on the top part of a mat. The participant was required to indicate their response to the statement read to them by placing the card under the Likert scale of their choice. The participant was requested to let the researcher/assistant know if clarification was required. At the end of the interview, the participant was asked how they found the interview process (D. Collins, 2003) specifically regarding the clarity of the questions when accompanied by the graphic symbols as well as regarding the flow and clarity of the interview.</p>	<p>and being sensitive to the needs of the participant.</p> <p><b>For the FSS:</b> The participant was able to understand each item and placed the graphic symbol card under their option of the Likert scale. At the end of the session, the participant expressed that this was a true representation of the sources of helpful support she has when raising her grandchild.</p> <p><b>For the SFS:</b> The participant was able to understand each item and placed the graphic symbol card under the option she felt she best related to in terms of how frequently she needed a specific type of help.</p> <p><b>For the PWBI:</b> The participant was able to understand the items of this measure. However, she had to be reminded of the scale in terms of the strongly agree to strongly disagree scale and the assistant occasionally had to re-read the item to her so that she could respond.</p> <p><b>For the PSS:</b> The participant asked the assistant to read the statements to her for certain items and seemed to have trouble remembering the rating of the Likert scale. The assistant provided the labels to the scale once more after rereading each statement to the participant, who was then able to respond with the graphic symbol card. At the end of the questions, the participant expressed an overall satisfaction with the process of the interview and that this method was insightful. For all the measures, it was</p>	<p>The procedure for all four measures was changed to the following: The participant was shown that the graphic symbol would be provided in the form of a booklet. The participant was provided with an explanation of the core concept represented by the picture, followed by the read statement together with the reminder of the scale labels. For each item, the participant pointed to their response on the scale while the researcher simultaneously recorded the response on the corresponding questionnaire. To ensure that the graphic symbols were easier to present, a standing-up A5 booklet was created of the graphics with the Likert scales below. The side facing the assistant contained the written instruction and item to be read to the participant. The suitability of the symbols was determined by the input of a person with low levels of literacy.</p>



Aim	Materials	Procedures	Results	Recommendations
To test the equipment for recording the interviews and the quality recording	Digital camera	A video of the interview was used to assist in ensuring procedural reliability. During the main data collection, the use of the video was for scoring purposes.	<p>suggested that the picture is explained (in terms of the core concept of the picture) so that the participant's frame of reference is in line with the statement being read. The participant further suggested that for the PWBI and PSS, because of the longer sentences of the items, a reminder of the scale of the statements of the measure would be helpful (e.g., for the PWBI – do you feel this never .../... quite often? For the PSS – do you strongly agree .../... disagree with this statement?).</p> <p>In terms of the presentation of the graphic symbols, the individual cards presented with problem as it was difficult for the researcher to manage the cards and to insert the data in the questionnaires.</p>	Because an audio recording would be required of the interviews, it was decided that an audio recording would be used with the booklet format. For the simultaneous scoring and voicing of the participant's response by the researcher, only an audio recording was required. Therefore, the Olympus Voice recorder was used instead of the video recorder.
To test the data capturing process the data to be used in SPSS	Excel spreadsheet	The pilot interview was captured on the survey materials (section A and Section B).	The statistician was consulted to prepare the template and the data capturing Excel spreadsheet. The statistician was also provided with the scoring criteria as originally devised by the authors of the measures to be used to calculate the scores for later data analysis.	No changes were made.

#### *4.5.1.2 Pilot Study 2*

The aim of Pilot Study 2 was to test the appropriateness of the graphic symbols to be used in the invitation letter, the consent form and the measures as described in Table 4.5. The participant easily understood the graphic symbols. The procedure of the Talking Mats™ framework proved to be challenging, as the various graphic symbols were in the form of loose cards. Instead, it was recommended that the graphic symbols and the text of each item of the measures be pasted in a booklet format to facilitate paging through each item. The clarity of the Likert scale from a 5-point to 4-point scale was also tested with no further changes required. This second pilot was also used to train the research assistants to 100% fidelity in terms of the procedure. Two practice sessions were held until the research assistants were able to carry out the procedures confidently and consistently. Due to the verbal presentation of the interview, it was recommended that the researcher voice and confirm the participant's response and, therefore, only a voice recorder was required. In terms of the data capturing process, it was recommended that the researcher capture the raw data on a Microsoft Excel spreadsheet so that the statistician could analyse the data in SPSS.

### **4.6. Main Study**

This section discusses the ethical considerations, data collection procedures, the preparation of data and the procedures in which the data were analysed.

#### **4.6.1. Ethical considerations.**

The study considered the following ethical principles as part of the procedures for the study. The study commenced only after receiving ethical approval from the Faculty of Humanities Research Ethics Committee of the University of Pretoria (Appendix U).

The grandparents were informed about the study and the aims of the study in the invitation letter. A brief outline of the procedures for data collection was also given. Participants were informed in the invitation letter (Appendices V1, V2 and V3) that the study would not expose them to physical or psychological harm. Participants were also informed that their involvement and participation in the study would be on a voluntary basis and that they were allowed to withdraw from the study should they wish to do so for any reason, without any negative consequences

(Ellis, 2014). The participants were informed that their confidentiality would be preserved with no mention of their name or identify, for example, each participant was coded as “P1” for “Participant 1”. They were also informed that the interview would be voice recorded. Furthermore, the participants were informed that the collected data would be stored securely at the Centre for Augmentative and Alternative Communication at the University of Pretoria for 15 years. The participants were made aware that, in order to avoid misuse of the data collected, it would be stored electronically and securely under a password that only the researcher would have for a time span of 15 years.

The consent form (Appendices V1, V2 and V3) confirmed the participant’s consent regarding their understanding of the voluntary condition of the participation in the study, their consent for the voice recording of the interview, their understanding that their confidentiality will be maintained and that they had the right to withdraw from the study at any time. To overcome the issue of low levels of literacy, the information within the invitation letter and consent forms was visually supported with graphic symbols and was also read aloud to each participant.

The research assistants and the procedural raters who assisted in the study signed a non-disclosure agreement (Appendix S) that specified that they would not discuss the grandparent interviews with other individuals. This was important to further protect the confidentiality of the participants of the study. Further ethical considerations were given to the provision of counselling to the grandparents during the interviews, due to the difficulty of their family, environmental and financial situations. The participants were given access to details of NGOs for support and they also received support during the interview as one of the research assistants was a social auxiliary worker.

#### **4.6.2. Research assistants.**

Two research assistants were recruited to assist in the data collection process as the researcher was not fluent in the two target languages (isiXhosa and Afrikaans). One assistant was fluent in English and isiXhosa and the other was fluent in English and Afrikaans. Table 4.6 provides details of the research assistants.

**Table 4.6: Background of Research Assistants**

<b>Language proficiency</b>	<b>Qualification</b>	<b>Current profession</b>	<b>Number of years working in disability</b>	<b>Number of years assisting in research</b>
isiXhosa	Social Auxiliary Worker	Research assistant and personal assistant at a non-governmental organisation	8 years	3 years
Afrikaans	Early Childhood Development Practitioner	ECD teacher at special needs school	2 years	1 year

In preparation for the data collection, the research assistants were trained because new research assistants had to be recruited after the pilot studies. The research assistants had the significant role of carrying out the structured interview with the participants because the researcher was not proficient in IsiXhosa and Afrikaans. The research assistants were selected on grounds of their past and current work experiences (see Table 4.6). They were also selected due to their involvement in and knowledge of the IsiXhosa and Afrikaans communities respectively, within the Western Cape, in which they live and have actively worked. The research assistants also educated the researcher regarding the various cultural norms within their respective communities. This was important for the researcher who is originally not from South Africa. Even though the researcher's role would be to only mark the participant's responses during the structured interview, it was still essential for the researcher to respect the cultural norms of the grandparents and their community (Research Center Survey, 2016). Furthermore, having the research assistant carry out the structured interview also contributed to a more relaxed atmosphere for the participant during the interview.

The aim of the training for each assistant was to ensure that they would conduct each interview in the same manner with each participant. Each research assistant was therefore familiarised with the aim of the study and the interview process which had to be followed with the procedural script. Each assistant was given the procedural script, after which the researcher and the assistant practised the interview process. The researcher and assistant also discussed possible problems which could arise during the interviews (Bragason, 1997). The assistants were familiarised with the expected mode of response from the participants. The assistants also received the participant invitation letter, the consent form and four booklets in the target language to familiarise

themselves with. Two rounds of practice sessions were carried out individually with each assistant and they were deemed ready when the researcher was satisfied with their ability to understand the rationale for the study, their confidence in following the procedural script and their ability to clearly read out the instructions and the items in the booklets.

During the training, the research assistants were reminded that it would be necessary to build rapport between themselves, the participant and the researcher by establishing a warm, trusting and supportive atmosphere during the interview which facilitates the sharing of information (Elmir et al., 2011). The assistants were also made aware that there was a likelihood that the grandparents may become emotional during the interview. Emotions were expected because the items of the measures related to the grandparents' daily struggles, their lack of support and possible accumulated and suppressed emotions. These emotions were bound to surface during the interviews because they were being given a platform to express themselves and were being heard (Elmir et al., 2011). For this reason, both the researcher and the assistant were aware of the importance of being in tune to the needs of the participant (Elmir et al., 2011). The non-disclosure form was further discussed with the research assistants to ensure the confidentiality of the grandparents who would be interviewed by the research assistant.

#### **4.6.3. Materials for recruitment of participants.**

The current section describes the different materials which were used in the main data collection of the study.

##### *4.6.3.1 NGO permission letter from researcher, NGO reply slip and sample questions.*

The permission letter to the NGOs (Appendix T) contained details such as the title of the study, the rationale for the study and the objectives of the study. Further details included what was expected of the NGO, and what would be expected of potential participants identified for the study. The declaration of participants' ethical rights was also included in the letter as well as information about how the data collected would be handled and stored securely.

A sample of one item from each of the four questionnaires (Appendix T) was provided to the NGO manager. These served as examples of how they would be presented to the participants.

A permission reply slip (Appendix T) indicated that the NGO was aware of the study and the researcher's intention to conduct the research at their organisation. The reply slip required the manager of the NGO to indicate the number of participants who they had identified as suitable for the study. This reply slip was also essential to gain final ethical approval from the University of Pretoria before data collection could begin.

#### **4.6.4. Interview pack**

In preparation for each interview with each participant, the researcher prepared a set of forms consisting of survey materials for Section A that comprised of the participant invitation letter, the participant consent form, the biographical questionnaire and the Ten Questions Questionnaire (TQQ) screening tool. The Section B survey consisted of the A5 booklets for each of the four measure and the scoring forms for each measure.

##### *4.6.4.1 Materials for Section A of survey*

The following materials were used for Section A of the survey.

##### *(a) Participant invitation letter and consent form*

The participant invitation letter contained details such as the purpose of the study, the procedure and what was expected of the participant, the participant's rights to participate being voluntary, the right to withdraw from the study and the maintaining of their confidentiality, and the management of the data provided by the participant. The participant consent form was used to record the confirmation of participant's understanding of the requirements of the study as well as the voluntary participation in the study. The consent form was adapted to contain graphic symbols in addition to the text for participants with low levels of literacy and written in simple language. The invitation letter and consent form were available in either English (Appendix V1), isiXhosa (Appendix V2) or in Afrikaans (Appendix V3), depending on which language the participant chose as their preferred language.

*(b) Biographical questionnaire*

The biographical information questionnaire was devised to collect information specifically related to the background of the grandparent caregiver, their family structure and financial situation, as well as details regarding their grandchild with a disability based on the conceptual framework and constructs of the current study. The biographical form was available to the participants in either English (see Appendix H1), isiXhosa (see Appendix H2) or in Afrikaans (see Appendix H3). Table 4.6 describes the justifications for the detail sought in the questions, together with the reference to supporting literature.

**Table 4.7: Biographical Information Form and Justification from Literature**

<i>Biographical information</i>	<i>Justification and support from literature</i>
	<b>Parenting grandparent</b>
Age of the grandparent	This information is important because it highlights the specific characteristics of the population of grandparents which are known to impact on the family patterns of interaction and eventual child developmental outcomes (Guralnick, 2011). With the increase in age, there is a greater likelihood that the overall health and well-being of the grandparent will deteriorate because age is also known to relate closely to the physical abilities of the individual and forms part of one of the characteristics of grandparent caregivers (Leder, Grinstead, & Torres, 2007).
Medical health problems	This information was used to describe the health status of the grandparent because they have a high likelihood of experiencing poor health with medical illnesses such as diabetes, hypertension, heart disease, asthma, arthritis and cancer (Muliira & Musil, 2010). This information is important because health problems which are known to affect the well-being of the caregiver, in turn, influences the quality of care the child receives (Muliira & Musil, 2010).
Education level	The education profile of the South African elderly has a high incidence of low literacy levels (Statistics South Africa & Lehola, 2014a). This information was used to describe the education level of the grandparents, which influences the amount of socio-economic resources they may receive and the amount of information they have access to regarding their health (Statistics South Africa & Lehola, 2014a) as well as the health of their grandchild with a disability.
Relationship with grandchild with a disability	This information helps to confirm that the participant's relationship to the child with a disability is that of a kinship relationship and is in relation to the statistical information that 7.8% of children are raised by their grandparents (Statistics South Africa, 2014b).
Reason and length of time for raising grandchild/ren	It has been the practice in South Africa for parents to send their children to be raised by their grandparent due to labour migration, premature death of a parent, incarceration or abuse (Mokone, 2006). The information regarding the reason why and the length of time that the grandparent was raising their grandchild was important due to the claims made in literature that

<i>Biographical information</i>	<i>Justification and support from literature</i>
	grandparents are known to become parents under forced and strained circumstances (Njororai & Njororai, 2013), such as the death of their adult child, abandonment of their grandchild, incarceration or drug use (Hayslip et al., 2014).
<b>Family structure and financial situation</b>	
Other family members living within the same household	This information was used to describe the household characteristics because families in South Africa that are usually composed of extended families living under the same roof are where financial challenges emerge among other prevalent social difficulties (Amoateng, Heaton, & Kalule-Sabiti, 2007). The presence of other family members has been shown to create forms of stress for grandparents (Lumpkin, 2007), especially where the other members are not contributors to the monthly family income (Njororai & Njororai, 2013).
Family's financial situation, source of income and employment status	This information was used to describe the financial status, source of income and the employment status of the grandparent, which ties into the finding that families are usually comprised of a large number of members, especially in the poorer areas (Statistics South Africa & Leholo, 2014a). The majority of parenting grandparents face financial troubles due to poor employment opportunities and poor financial help from other sources such as family. However, the receipt of grants are accessed by a large amount of grandparent caregivers (Mokone, 2006).
Other financial help from family	This information was used to describe the presence of financial help provided to the grandparent as this is a resource which is often strained due to the additional care needed by their grandchild with a disability (Kresak, Gallagher, & Kelley, 2014). The financial resource and help is often highly needed for grandparents who are already struggling, which in turn impacts on the levels of stress and impact on their well-being (Dolbin-Macnab et al., 2016).

(c) *Ten Questions Questionnaire screening tool*

The Ten Questions Questionnaire (TQQ) screening tool was devised by Durkin, Zaman, Thorburn, Hasan and Davidson (1991). It has been used extensively in a number of developing countries such as Pakistan, Bangladesh and South Africa (Christianson et al., 2002; Giarelli, Clarke, Catching, & Ratcliffe, 2009; Kromberg et al., 2008). This brief screening tool assisted in obtaining information regarding the characteristics of the grandchild's disability with a specific focus on the detection of moderate to severe disabilities related to sensory issues, seizures as well as speech delays (WHO, 1992). During the recruitment process, the center managers assisted with the identification grandparents of only children born with a disability (see Appendix U), according to their medical records, to ensure that the grandchild had a congenital form of disability.



The TQQ is composed of ten questions that ask specific information related to a category of disability, based on comparison to other peers of the child within the same cultural context (Giarelli et al., 2009). For example, for developmental delays, a question asks, “compared with other children, does or did (name of child) have any serious delay in sitting, standing, or walking?”, where after the caregiver responds with either “yes” or “no”. A positive result is obtained if one or more of the items in the TQQ indicate a problem and a negative result if the responses indicate normal development (WHO, 1992).

The TQQ has undergone a number of validity and reliability tests in several low- and middle-income countries, such as Bangladesh, Pakistan and Jamaica (Durkin, Hasan, & Hasan, 1995; Zaman et al., 1990). The TQQ has been found to have excellent sensitivity to disorders related to motor, seizures, speech, vision and hearing (Durkin et al., 1995). Firstly, in terms of its validity, the TQQ showed no bias regarding the age and gender criteria. Secondly, it is a sensitive tool in identifying moderate to severe disabilities in children between the ages of two and nine years. Finally, the TQQ has contributed to the evaluation efficiency of children who would require professional evaluation. These validity characteristics of the TQQ were considered in the current study since, within the communities, the children may not all have had a formal diagnosis, or the caregivers may not always know the formal name of the diagnosis of the child’s disability.

The TQQ has also been found to have a good reliability of 0.60 when tested in the various countries (Durkin et al., 1995). For these reasons, the TQQ was an important tool to include as a means of ensuring that the grandchild of the grandparent did in fact have a diagnosis as a criterion for participating in the study. The only area that was found to require further in-depth testing was for the detection of disability related to vision and hearing (Durkin et al., 1995). For the current study, although it was not essential to have the exact severity of vision and hearing of the grandchild, absence of vision and hearing was enough to provide a decision of what areas were impacted by the disability for the grandchild. The TQQ was available to the participants in English (Appendix H1), isiXhosa (Appendix H2) and Afrikaans (Appendix H3), depending on their preference.

#### 4.6.4.2 Materials for Section B of survey.

This section describes the materials used in Section B of the survey.

##### (a) *Measures booklets (Section B)*

For the PSS, PWBI, SFS and FSS, an A5 spiral-bound flip-booklet in landscape format was created in each language with one side for the interviewer in English (Appendix I1), isiXhosa (Appendix I2) and Afrikaans (Appendix I3) and the other side for the respondent in English (Appendices J1), isiXhosa (Appendix J2) and Afrikaans (Appendix J3). For each measure, every item was presented with its Likert scale response on the same page. These were printed and pasted into the booklet.

A total of twelve books (Appendix K) were made for all four measures in all three languages, where each printed page was colour coded for each of the four measures (PSS – blue, PWBI – green, SFS – yellow, FSS – pink). For each of the three languages, the booklets were labelled with coloured tape (English – purple, isiXhosa – orange and Afrikaans – turquoise) to make it easier to find and select the booklets during the interviews. It was ensured that the main instruction for each measure was situated on the first page on the interviewer’s side together with each item and the scoring responses so that these could be repeated at each item for the participant after the item had been read. On the respondent’s side, only the item as well as the Likert response scale were provided and all text was kept to font size 14 (Meadows, 2003). The graphic symbols acted as visual support for each item and response option (Batorowicz et al., 2017).

##### (b) *Measure of caregiving stress (Section B)*

The original measure of the PSS as devised by Berry and Jones (1995) (Appendix A) contains 18 items that tap into positive experiences such as emotional benefits of caregiving and personal development, while the negative experiences include demands on resources and restrictions due to caregiving. A 5-point Likert rating scale is used which ranges from “*strongly disagree*” (1), “*disagree*” (2), “*undecided*” (3), “*agree*” (4) to “*strongly agree*” (5). High levels of stress were

indicated by the high score of the total of the items. The measure is reported to have an internal reliability of 0.83 with a test-retest reliability of 0.81 (Berry & Jones, 1995)

For the current study, adaptations were made to the PSS to suit the grandparent caregiver. These adaptations are further discussed in Phase 2 of Adaptations of the Measures. The final PSS was composed of the same 18 items with graphic symbols to represent the core concept of each of the items. The PSS was translated (described in section 3.4.3 in the Chapter 3) from English (Appendices I1 and J1) to isiXhosa (Appendices I2 and J2) and Afrikaans (Appendices I3 and J3).

(c) *Measure of well-being (Section B)*

The original measure of the PWBI as devised by Trivette and Dunst (1986) (Appendix B) focuses on both personal and general well-being as well as child-related well-being in light of caregiving responsibilities. Four specific constructs of well-being which are measured include general emotional well-being, general physical well-being, child-related emotional well-being and child-related physical well-being. These four constructs are measured by four items, each with a total of 16 items in the scale. The scale is reported to have a reliability of 0.88 (Trivette & Dunst, 1986). The response method is in the form of a five-point Likert frequency scale ranging from “never” (1) to “quite often” (5). Permission was obtained from Winterberry Press to use and adapt the PWBI in the current study (Appendix E).

The PWBI used in this study was adapted and described in Phase 2 of Adaptations of the Measures (Appendices I1 and J1) to isiXhosa (Appendices I2 and J2) and Afrikaans (Appendices I3 and J3).

(d) *Measures of perceived social support (Section B)*

Two questionnaires were used to measure the perceived social support of the grandparents, namely the Support Functions Scale (SFS) and the Family Support Scale (FSS).

*Perceived need for types of support*

The original SFS (Appendix C) by Dunst and Trivette (1986) was devised on parents of a child with disabilities, delays or risk of poor developmental outcomes to measure the parents' need for

different types of social support, such as emotional support, financial support, child support, instrumental support and agency support. The authors of the SFS initially created an extended version consisting of 20 items and then a shortened version consisting of 12 items. The shortened 12-item version was used in the current study. Each item of the original scale is scored on a 5-point Likert frequency scale which ranges from “*never*” (1), “*once in a while*” (2), “*sometimes*” (3), “*often*” (4) to “*quite often*” (5). The reliability of the scale was reported to be 0.87 (Trivette & Dunst, 1986). Permission was obtained from Winterberry Press to use and adapt the SFS in the current study (Appendix E).

The modifications which were done to the SFS are discussed in detail in the Section 3.3 in Phase 2 of Adaptations of the Measures. Graphic symbols were used to represent the core concept for each of the 12 items of the SFS. The SFS was translated from English (Appendices I1 and J1) to isiXhosa (Appendices I2 and J2) and Afrikaans (Appendices I3 and J3).

*Perceived helpfulness of available sources of support*

The FSS by Dunst et al. (1984) was devised on parents of a child with a diagnosed disability or at risk for developmental delay to measure the helpfulness of various sources of social support received, such as kinship, family members, social organisations, informal supports, as well as professional services. The scale is composed of 20 items scored on a 5-point rating scale ranging from “*not at all helpful*” (1) to “*extremely helpful*” (5). The FSS is reported to have a reliability of 0.79 (Dunst et al., 1984). However, within the current study, the reliability of the scale presented as being inadequate (between 0.07 and 0.51) (Kline, 2011), resulting in its exclusion from the analysis process in section 5.2.1.4 of Chapter 5. Permission was obtained from Winterberry Press to use and adapt the FSS in the current study (Appendix E).

Adaptations of the FSS were made using graphic symbols and further details regarding these adaptations are discussed in the Section 3.3 of Phase 2 of Adaptations of the Measures. The FSS was translated from English (Appendices I1 and J1) to isiXhosa (Appendices I2 and J2) and Afrikaans (Appendices I3 and J3).

*(e) Scoring forms*

A scoring form was created for the PSS (Appendix L), the PWBI (Appendix M), the SFS (Appendix N) and the FSS (Appendix O), which contained each item, the possible scores as well as the scoring criteria from the authors of the measures (Berry & Jones, 1995; Dunst & Trivette, 1986; Dunst et al., 1984; Trivette & Dunst, 1986).

**4.6.5. Materials for data collection reliability**

The following materials were used for the procedural reliability of the data collection process.

*4.6.5.1 Procedural script and checklist for conducting the semi-structured interview*

A procedural script in English (Appendix Q1), isiXhosa (Appendix Q2) and Afrikaans (Appendix Q3) was used to guide the research assistant regarding the procedures to be followed during the structured interviews. The procedural script also ensured consistency in the instructions to the participants during the data collection; for example, the procedure of how the participant was required to respond to the questions. The procedural checklist (Appendix R) was filled out by independent raters (section 4.6.10.2) to ensure that each procedure had been completed as required.

**4.6.6. Community resource flyer**

A community resource flyer (Appendix P) was provided to each participant, which highlighted the existing resources available to meet the specific needs identified in the completion of the SFS measure. Community resource mapping is a strategy used to organise information and to provide a clear direction to meet the needs of the individual (Crane & Mooney, 2005). Before each interview, the researcher and the research assistant established the contact details, physical locations and operating hours of different NGOs closest to and within the community of the grandparents who would be interviewed. The information was organised in the order of the types of support provided by the NGOs; for example emotional support (abuse and violence helplines and mental health line), grandparent support groups, financial support (grant offices), childcare

support (respite care) as well as emergency numbers such as police, ambulance, hospital and fire department. The flyers varied according to the NGOs available in and around that specific community. The information in the flyers was provided in all three target languages; that is, isiXhosa, Afrikaans and English. At the end of each interview, the flyer was explained and provided to the participant.

#### **4.6.7. Equipment**

##### *4.6.7.1 Voice recorder*

An Olympus VN-2100PC digital voice recorder was used to record the interview during the data collection process.

#### **4.6.8. Procedures**

This section contains the general procedures which were followed for the data collection.

##### *4.6.8.1 General procedures*

Ethical approval was first received from the Faculty of Humanities Research Ethics Committee of the University of Pretoria (Appendix T). Before the recruiting of grandparent caregivers for the study commenced, permission was obtained from relevant NGOs. Once the NGOs had agreed to take part in the study, the manager was required to complete the reply slip (Appendix U), which was sent to the University of Pretoria for Final Ethical Approval. Once approval had been granted, the managers provided the researcher with the contact details of the participants who they had identified as meeting the selection criteria for the study. The researcher consulted with the head of the Ethical Board of the Western Cape Department of Social Development (WCDSD) regarding the required procedures for obtaining permission to the NGOs and Special Care Centres. However, the researcher was informed that no permission was required from the WCDSD as the NGOs and Special Care Centres were not under the jurisdiction of the Department. Therefore, the researcher was permitted to contact the managers of these sites

directly using a database provided by the DSD, which proved to be a useful starting point for data collection.

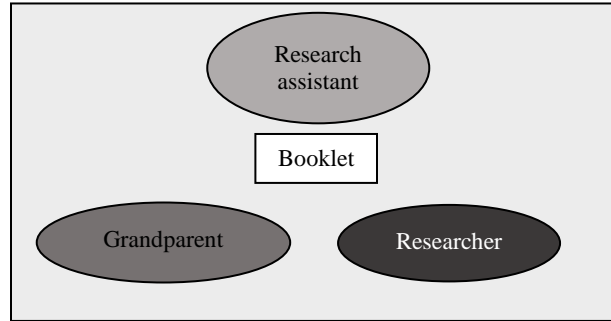
The managers of each NGO and Special Needs Care Centre were contacted via email, telephonically and visited in person to establish a rapport with the managers. The background of the study was discussed, and the managers were provided with a checklist of the selection criteria for the participants. The managers then advised the researcher whether they would have suitable participants. If so, the necessary logistical issues around the best way to access the participants was discussed with the managers. For each manager, a pack was prepared containing the NGO's permission letter to recruit participants, examples of items from the four questionnaires, an example of the participant invitation letter and the participant consent form as well as a permission reply slip to be completed and returned to the researcher for further ethics approval.

#### *4.6.8.2 Data collection procedures*

Before the interviews, the researcher prepared the interview packs. These contained the invitation letter and consent form (Appendices V1, V2 and V3), the biographical questionnaire together with the TQQ screening tool (Appendices H1, H2 and H3), the scoring forms of the PSS (Appendix L), PWBI (Appendix M), SFS (Appendix N) and the FSS (Appendix O), the community resource flyer (Appendix P) each participant as well as the easy-to-read summary pamphlet of the study (Appendix W1, W2, W3) for the participants who required this.

#### *4.6.8.3 Settings*

Most of the grandparents were interviewed in their living room. In one instance, the grandparent who lived in a hostel requested for the interview to be carried out in her room next to her bed as this represented her own personal space where no one would interrupt the interview. The researcher was always seated beside the grandparent to see which graphic symbol the grandparent pointed to, as set out in the seating arrangement of Figure 4.3.



**Figure 4.3: Seating Arrangement for the Interview**

To ensure that the grandparent's responses were not influenced by the people around the home, the grandparent was given a choice of whether they preferred the interview to be conducted on another day when there would be fewer people in the home. In other cases where the grandparent felt at ease with their other relatives being present in the home, the interview continued. In whichever context the interview took place, the researcher ensured that the grandparents were comfortable to carry out their interview.

At the beginning of every interview, the grandparents were advised that information would be presented to them in the form of pictures and words and they were therefore prepared in case they needed to wear their spectacles. The researcher provided the research assistant with the interview pack (Appendices V1, V2 and V3) for the information from the invitation letter, consent form and the biographical information form to be read aloud to the grandparent. Thereafter, the grandparent completed the consent form where, on consent to participate, the participant signed or added their thumb print to the form. The researcher then switched on the voice recorder and the research assistant proceeded by reading out the instructions with the interview, while keeping to the procedural script (Appendices Q1, Q2 and Q3) for completion of the Section A and Section B of the interview. The research assistant completed the Section A with the participant under the supervision of the researcher to ensure there was no missing or incorrect data. Following this, the participant was then informed that the assistant would be reading out the questions to them and the researcher would be marking their response. The research assistant therefore read aloud each question of the Section B to the grandparent and the researcher marked the participant's responses on the scoring form (Appendices L, M, N and O). The assistant confirmed the participant's response in English so that the researcher knew which response to mark.



The interview then proceeded with Section B of the survey, which entailed the use of the response booklets (Appendix K). First was the PSS booklet, followed by the PWBI booklet and then the SFS booklet. The session ended with the FSS booklet. A flat surface was required to display the booklets and to keep them upright. Since it was not guaranteed that a flat table surface would be available in every context where the interview was due to take place, a clipboard with a rubber mat was used as part of the material. The research assistant then proceeded to read aloud the instructions as well as each item and the possible responses on the Likert scale. The researcher also had the role of pointing to each graphic symbol of the response options for the grandparent while these were being read aloud for each item. This ensured consistency in the responses as well as correctly scoring of the responses. Each response was voiced by the researcher for the voice recorder to be used for data checking at a later stage.

The participant was given sufficient time to think about their response; when required, questions were repeated or clarified. The researcher and her assistant were sensitive to the participant's emotions during the interview in order to gauge whether the participant was tired or too emotional to continue (Elmir et al., 2011). A short break of approximately five minutes was provided if the participant found the process tiring, intense or overwhelming. At the end of the interviews, the participant was given an opportunity to ask the researcher questions and to express how they felt about the interview process. As a means of ensuring that the participants had sources of support they could access, they were provided with a community resource flyer of available support services within their community. Finally, a small token of appreciation was presented to the participant after the interview in the form of a gift hamper (worth R150 or \$10). Each interview lasted approximately one to one and a half hour, depending on how comfortable the grandparent felt to speak and share information. Although this extra information was not required for the data collection, the grandparents were not discouraged to speak since, for many of them, this was the first time they were given a platform to express how they truly felt as caregivers raising their grandchild with a disability.

#### 4.6.9. Scoring.

The raw scores for each participant were recorded on the scoring form, where the researcher circled the option to which the participant pointed and voiced. After the interviews, the scores were then captured in a Microsoft Excel spreadsheet. Each item of Section A and Section B was displayed in the spreadsheet designed in consultation with the statistician according to the data type; that is, ordinal or continuous data accordingly. Each participant was given a code (e.g., P1, P2).

#### 4.6.10. Data reliability

The data collected at the end of every interview were transferred to the Excel spreadsheet. Another independent rater checked the data after every entry to ensure that there were no errors or missing data in the preparation for data analysis.

#### 4.6.11. Data preparation and data analysis procedures.

The various statistical procedures that were followed and their rationale are described in Table 4.8 according to each of the sub-aims which were set out for the study.

**Table 4.8: Statistical Procedures Used for Each Sub-aim**

Sub-aim of study	Statistical procedure and rationale
1. To describe and analyse the relationship between perceived social support and caregiving stress.	Linear regression: to determine the nature and the extent of the relationship between the constructs of perceived social support and caregiving stress (Kline, 2011) .
2. To describe and analyse the relationship between perceived social support and grandparent well-being.	Linear regression: to determine the nature and the extent of the relationship between the constructs of perceived social support and well-being (Kline, 2011).
3. To describe and analyse the relationship between caregiving stress and well-being.	Linear regression: to determine the nature and the extent of the relationship between the constructs of caregiving stress and well-being (Kline, 2011).
4. To describe and analyse types of effect of perceived social support on the relationship between caregiving stress and grandparent well-being.	i) Sobel Test: to identify the presence of any mediating or moderating effect of perceived social support on the relationship of caregiving stress and well-being (Kline, 2011). ii) Partial Least Squares Structural Equations Model (PLS SEM) to analyse the degree of mediating or moderating effect of perceived social support on the relationship of caregiving stress and well-being (Kline, 2011).

Sub-aim of study	Statistical procedure and rationale
5. To describe and analyse the relationship between the three constructs and the reported demographics of the: <ul style="list-style-type: none"> <li>i) grandparents in terms of the type of grandparent caregiver</li> <li>ii) the grandparent's age</li> <li>iii) the monthly household income</li> <li>iv) the grandparent's perceptions of their financial status</li> </ul>	For variables i) to iii) one-way ANOVA was used to compare variations between the variables and the constructs of PSS, PWBI and FSS (Kline, 2011). For variable iv) Kruskal-Wallis was used to analyse if there were any differences between the grandparent's financial perceptions in relation to the PSS, PWBI and SFS (Kline, 2011) .

As described in Table 4.8, statistical analysis was carried out by a statistician using IBM Statistical Package for Social Science (SPSS). ANOVA was used to analyse the variables of the biographical data and the TQQ screening tool. Further analysis included descriptive statistics for each item of the measures to identify the variability in the scores and to compare the data. Specific descriptive data also included the means and standard deviations for each item provided as well as the p-values for each of the sub-scales of the measures. A series of separate linear regressions (Gefen, Straub, & Boudreau, 2000) was carried out to analyse the nature and extent of the relationships between the measures. Linear regression is deemed to be the most appropriate method of analysing the relationships between the constructs because of the small sample size of this study (Gefen et al., 2000). Following this, the data were analysed using the Sobel Test (Kline, 2011) to identify the presence of any mediating or moderating effects between the data of the measures. Finally, Partial Least Squares Structural Equations Model (PLS SEM) was used to provide further information regarding the degree of mediations and moderation between the data of the measures.

#### 4.6.11.1 Reliability

For each measure, namely the PSS, PWBI, SFS and FSS, the reliability was evaluated by evaluating the internal consistencies of the measures by calculating the Cronbach's alpha (as discussed in section 5.2 in Chapter 5). The reliability of the scales ensured that the measures were at least adequate to include in further analysis (Kimberlin & Winterstein, 2008).

#### 4.6.11.2 Procedural reliability of the procedural checklist

To ensure procedural integrity for each of the structured interviews across all three language groups (English, isiXhosa and Afrikaans), a procedural checklist (Appendix R) was created. The procedural checklist was completed by two raters. One rater was fluent in isiXhosa as their home language and the other in Afrikaans. Both raters were also fluent in English. The raters completed the procedural checklists for the interviews which had been conducted in their home language. The Afrikaans rater also rated the English interviews.

According to Jenkins and Reed (2016), there is currently no gold standard for how many procedures need to be monitored. However, as a safety measure, no fewer than ten procedures for a small sample size is recommended or 20% to 40% of the sample size (Schlosser, 2005). Therefore, a total of 13 procedural checks (5 isiXhosa, 5 Afrikaans, 3 English) were conducted, which accounted for 26% of the 50 interviews. Only three interviews were rated in English as this was the total number of interviews in this language compared to the other two languages. The procedural checklist contained a total of 26 steps (with a ceiling of 338 correct steps for the 13 procedural checks). The totals of the procedural checks of the three languages are presented in Table 4.9.

**Table 4.9: Procedural Reliability Scores for Procedural Script**

Number of procedural steps followed	Total correct procedural steps followed			
	English	IsiXhosa	Afrikaans	
1. Introduction section	25	24	26	
2. Receipt of consent	26	26	26	
3. Section A (Biographical information and TQQ form)	24	24	24	
4. Section B (Booklets)		26	26	
		26	25	
<b>Total correct steps followed</b>	<b>75</b>	<b>126</b>	<b>127</b>	<b>Total 328</b>

According to McMillan and Schumacher (2010), the procedural reliability is calculated as below to provide a percentage of reliability:

$$\frac{\text{Total number of correct steps (328)}}{\text{Total number of steps (338)}} \times 100 = 97\% \text{ procedural reliability}$$

A high score of 97% of procedural reliability was achieved, which was expected due to the strict script that guided the procedure.

#### **4.7. Summary**

This chapter presented the main aim, sub-aims and research design which applied in the current study. Details of the participant recruitment in terms of the sampling, the participant selection criteria and the descriptions of the participants were provided. The chapter also supplied details of the pilot studies which were carried out prior to the main data collection. The main study was described, which included details regarding the ethical considerations, the materials used, the research assistants and the procedures which were followed. The study concluded with details on the scoring procedures, the preparation of the data prior to analysis as well as the methods which were used to ensure reliability of procedures for the study.

## Chapter 5: Results

### 5.1. Introduction

The chapter begins with a description of the reliability of the Parental Stress Scale (PSS), the Personal Well-Being Index (PWBI), the Support Functions Need (SFS) and the Family Support Scale (FSS). It includes a discussion regarding the exclusion of the FSS. This is followed by the descriptive statistics of the PSS, the PWBI and the SFS. Next, an analysis of the correlations and relationships between the included measures, namely the SFS, the PSS and the PWBI, is presented based on the hypotheses set in Chapter 4. Further analysis is described regarding the types of effect (mediating or moderating) of the SFS on the relationship of the PSS and PWBI. Finally, to further understand the results in the context of the grandparents, further correlations are described in terms of the relationships between the reported type of grandparent caregiver, their age, their monthly household income and their perceptions of their financial status.

### 5.2. Reliability

In this section, the internal consistency for the instruments used in this study, namely the PSS, the PWBI, the SFS and the FSS, is presented.

#### 5.2.1. Instrument reliability

To determine the instrument reliability, the internal consistency of each instrument was determined. The internal consistency is an estimate of the reliability of the measurement based on the assumption that there should be a correlation between the items that are measuring the same construct (Kimberlin & Winterstein, 2008). The internal consistencies of the PSS, the PWBI, the SFS and the FSS were measured with the Cronbach's alpha ( $\alpha$ ). Conventionally, the reliability score should be greater than or equal to 0.70 to 0.80. A Cronbach's alpha close to 0.90 is considered to be "excellent", 0.80 is considered to be "good", 0.70 to 0.50 is considered to be "adequate" and less than 0.50 is considered to be "inadequate" (Kline, 2011).

### 5.2.1.1 The reliability of PSS

The Cronbach's alpha for all sub-scales of the PSS is presented in Table 5.1. The measure is reported to have an internal reliability of 0.83 with a test-retest reliability of 0.81, according to the authors of the PSS (Berry & Jones, 1995). In the current study, the PSS sub-scales all had an adequate reliability (between 0.70 and 0.50), except for the sub-scale of attachment, which had an inadequate score (0.44). The items in this sub-scale of "attachment to child" were reverse-scored, which, according to (Weijters, Baumgartner, & Schillewaert, 2013), reduces the reliability of a sub-scale based on the participant's perception of the question or the item. No items were removed.

**Table 5.1: Reliability of PSS**

Domains	Sub-scale	Number of Items	$\alpha$	Interpretation
Child domain sub-scales	Demandingness of caregiving	7	0.66	Adequate
	Child behaviour	3	0.53	Adequate
Parent domain sub-scales	Sense of self-competence	4	0.74	Adequate
	Attachment to child	4	0.44	Inadequate
	Role conflict	2	0.58	Adequate

### 5.2.1.2 The reliability of the PWBI

Table 5.2 illustrates the Cronbach alpha for all the sub-scales of the PWBI. The scale is reported to have a reliability of 0.88 by the authors (Trivette & Dunst, 1986). The four sub-scales which constitute the scale all had adequate reliability (between 0.57 and 0.73). No items were removed from this scale.

**Table 5.2: Reliability of PWBI**

Domains	Sub-scales	Number of Items	$\alpha$	Interpretation
General Well-Being	General Emotional	4	0.73	Adequate
	General Physical	4	0.57	Adequate
Child-Related Well-Being	Child-Related Emotional	4	0.66	Adequate
	Child-Related Physical	4	0.67	Adequate

### 5.2.1.3 The reliability of the SFS

The Cronbach alpha for each sub-scale of the SFS is illustrated in Table 5.3. The reliability of the scale was reported to be 0.87 (Dunst & Trivette, 1986). The one sub-scale of “agency support” was not considered as it was a single-item sub-scale. For the other four sub-scales, all had adequate reliability scores (between 0.73 and 0.86) and no further items were removed from this scale.

**Table 5.3: Reliability of SFS**

Sub-scales	Number of Items	$\alpha$	Interpretation
Emotional support	4	0.77	Adequate
Child support	3	0.73	Adequate
Financial support	2	0.59	Adequate
Instrumental support	2	0.58	Adequate
Agency support*	1		

\*This sub-domain is based on a single item, therefore an alpha is not presented

### 5.2.1.4 The reliability of the FSS

The Cronbach alpha for the FSS is illustrated in Table 5.4. The FSS is reported to have a reliability of 0.79 (Dunst et al., 1984).

**Table 5.4: Reliability of FSS**

Sub-scales	Number of Items	$\alpha$	Interpretation
Kinship	2	0.16	Inadequate
Spouse/Partner support	3	0.26	Inadequate
Informal support	9	0.51	Adequate
Programmes/Organisations	5	0.07	Inadequate
Professional services	3	0.22	Inadequate

Compared to the PSS, PWBI and the SFS, most of the FSS sub-scales presented with poor to inadequate reliability (between 0.07 and 0.51), when considering the interpretation of the ratings of the Cronbach  $\alpha$  by Kline (2011). For the FSS, it is postulated that the poor internal consistencies were possible due to several reasons. According to Kline (2011), psychological constructs which are measured in diverse ways tend to present with lower than 0.7 reliability scores. In studies that have analysed the psychometric properties of the FSS (Hanley, Tasse,



Aman, & Pace, 1998; Littlewood, Swanke, Strozier, & Kondrat, 2012), the Cronbach  $\alpha$  for each sub-scale is reported to be for:

- i) kinship 0.58 (Littlewood et al., 2012) and 0.65 (Hanley et al., 1998);
- ii) spouse/partner support 0.82 (Littlewood et al., 2012) and 0.78 (Hanley et al., 1998);
- iii) informal support 0.64 (Littlewood et al., 2012) and 0.74 (Hanley et al., 1998);
- iv) programmes/organisations 0.62 (Littlewood et al., 2012); and
- v) professional services 0.60 (Hanley et al., 1998).

The Cronbach  $\alpha$  scores from these two studies of Littlewood et al. (2012) and Hanley et al. (1998) show that the reliability of the sub-scales can vary between a “good” to “adequate”. However, these scores have been established among a large sample of participants, where Littlewood et al. (2012) had (N = 2,956) participants and Hanley et al. (1998) had (N = 244) participants compared to the current study where there were only (N = 50) participants. It is further not possible to generalise the reliability scores of the FSS from other studies due to the context of the current study, where factors such as socio-economic background and the presence of the disability factor of the grandchild are likely to influence the applicability of the measure (Marfo & Pence, 2009). Moreover, Littlewood et al. (2012) also highlighted that part of the scoring criteria of the FSS may be an issue; if a source of support was not available to the grandparent, it would be treated as missing data. In the current study there was a high unavailability of sources of support for which the grandparents obtained a score of “0”, further marked as “not available”. It is therefore possible that the high number of unavailable support sources may have influenced the total scores which the grandparent received on the FSS.

Furthermore, the Cronbach  $\alpha$  of a scale is reliant on the number of items in the scale, where a small number of items will lead to lower levels of Cronbach  $\alpha$  (Kimberlin & Winterstein, 2008). This is seen in the FSS, where there are sub-scales which were comprised of between 2 to 5 items measuring the helpfulness of kinship support, spouse/partner support and programmes/organisations. The only sub-scale which had an adequate reliability in the FSS was the “informal support” which was composed of nine items. Alternatively, one could also argue

that the participants did not understand the items. However, owing to the simplicity of the items, this is highly unlikely. There was no significant change in the Cronbach alphas if items were deleted. Considering these various reasons for the poor reliability of the FSS, Kline (2011) cautions regarding the inclusion of measures with poor reliability, where there is a risk of “reducing the power of statistical tests” (Kline, 2011, p. 70). For this reason, the FSS was not included in further analysis.

### **5.3. The Results of the Grandparent Caregiver Stress (PSS)**

The PSS was used to measure the construct of caregiving stress which was made up of the child domain and parent domain. The child domain was measured by the “demandingness of caregiving” and the “child behaviour” sub-scales. The parent domain was measured by the “sense of self-competence”, “attachment to child” and the “role conflict” sub-scales. Each item from the five sub-scales was scored on a 5-point Likert-type scale ranging from 5.00 (*strongly agree*) to 1.00 (*strongly disagree*).

As part of the scoring criteria, the items within the “role conflict” domain and the “attachment to child” domain were reverse-scored due to the numerical scoring occurring in the opposite direction to the other items in the other domains. These two sub-scales had items which were positively worded; for example, “you are happy with your role as a caregiver”. Therefore, a lower total score in these domains would indicate low caregiving stress within these domains. The reversing of the scores was necessary for comparing the role conflict and attachment to the child sub-scales with the other sub-scales. A total score was obtained by adding the scores. The higher the scores obtained on these sub-scales, the higher the levels of caregiving stress.

#### **5.3.1. Child domain**

This domain contained sub-scales measuring caregiving stress of the grandparent caregivers related to the demandingness of caregiving and the child behaviour.

##### *5.3.1.1 Demandingness of caregiving*

The mean scores and standard deviations for the sub-scale of demandingness of caregiving under the child domain are presented in Table 5.5.

**Table 5.5: Means and Standard Deviations for Demandingness of Caregiving of the PSS (N = 50)**

<b>Demandingness of caregiving items</b>	<b>Strongly disagree n (%)</b>	<b>Disagree n (%)</b>	<b>Undecided n (%)</b>	<b>Agree n (%)</b>	<b>Strongly agree n (%)</b>	<b>Mean</b>	<b>SD</b>
Caring for grandchild takes more time and energy	4 (8)	2 (4)	0	22 (44)	22 (44)	4.12	1.15
Too little control over own life	4 (8)	11 (22)	1 (2)	14 (28)	20 (40)	3.70	1.40
Grandchild is a major source of stress	15 (30)	12 (24)	0	12 (24)	11 (22)	2.84	1.60
Too little time and flexibility in life due to raising grandchild	11 (22)	9 (18)	1 (2)	12 (24)	17 (34)	3.30	1.62
Raising grandchild is a financial burden	10 (20)	10 (20)	0	9 (18)	21 (42)	3.42	1.65
Might never do it again	15 (30)	17 (34)	5 (10)	3 (6)	10 (20)	2.52	1.49
Raising grandchild has meant having too few choices	12 (24)	12 (24)	1 (2)	11 (22)	14 (28)	3.06	1.61

As illustrated in Table 5.6, the mean scores for all the items were varied ranging from a minimum of 2.52 to a maximum of 4.12. These results show that the item of “caring for grandchild takes more time and energy” had the highest response of agreement, where 44% ( $n = 22$ ) of the grandparents strongly agreed with this statement ( $M = 4.12$ ,  $S.D = 1.15$ ). On the other hand, the lowest level of stress was noted for the item of “might never do it again”, where 34% ( $n = 17$ ) of the grandparents disagreed with this statement ( $M = 2.52$ ,  $S.D = 1.49$ ), indicating that the grandparents would raise their grandchild again if they had to do so.

### 5.3.1.2 Child behaviour

The mean scores and standard deviations for the sub-scale of child behaviour under the child domain are presented in Table 5.6.

**Table 5.6: Means and Standard Deviation for Child Behaviour (N = 50)**

<b>Child behaviour items</b>	<b>Strongly disagree n (%)</b>	<b>Disagree n (%)</b>	<b>Undecided n (%)</b>	<b>Agree n (%)</b>	<b>Strongly agree n (%)</b>	<b>Mean</b>	<b>SD</b>
Grandchild’s behaviour is stressful	6 (12)	10 (20)	0	13 (26)	21 (42)	3.66	1.49
Behaviour of grandchild is embarrassing	26 (52)	16 (32)	0	4 (8)	4 (8)	1.88	1.26
Grandchild is enjoyable (reversed)	1 (2)	2 (4)	1 (2)	6 (12)	40 (80)	1.36	0.88

The item of “grandchild’s behaviour is stressful” was the highest scored item ( $M = 3.66$ ;  $S.D = 1.49$ ), with 42% ( $n = 21$ ) of the grandparents strongly agreeing with this statement. For the statement of “grandchild is enjoyable” ( $M = 1.36$ ;  $S.D = 0.88$ ), 80% ( $n = 40$ ) of the grandparents strongly agreed with this statement, indicating that they enjoyed their grandchild.

### 5.3.2. Parent domain.

This domain measured the caregiving stress of the grandparent caregivers related to the sense of self-competence, attachment to the grandchild and role conflict.

#### 5.3.2.1 Sense of self-competence

The mean scores and standard deviations for the sub-scale of sense of self-competence under the parent domain are presented in Table 5.7.

**Table 5.7: Means and Standard Deviations for Sense of Self-Competence (N = 50)**

Sense of self-competence items	Strongly disagree	Disagree	Undecided	Agree	Strongly agree	Mean	SD
	n (%)	n (%)	n (%)	n (%)	n (%)		
Worry whether doing enough grandchild	3 (6)	4 (8)	0	18 (36)	25 (50)	4.16	1.17
Positive view for the future when raising grandchild (reversed)	0	2 (4)	0	16 (32)	32 (64)	1.44	0.70
Difficulty balancing different responsibilities because of grandchild	13 (26)	8 (16)	0	17 (34)	12 (24)	3.14	1.59
Overwhelmed by caregiver responsibility	12 (24)	17 (34)	0	6 (21)	15 (30)	2.90	1.63

The item of “worry whether doing enough grandchild” showed that a high number of 50% ( $n = 25$ ) of the grandparents strongly agreed with this ( $M = 4.16$ ;  $S.D = 1.17$ ). For the item of “positive view for the future when raising grandchild”, 64% ( $n = 32$ ) of the grandparents strongly agreed with this item ( $M = 1.44$ ;  $S.D = 0.70$ ), indicating a resultant low stress score since this item was reversed.

#### 5.3.2.2 Attachment to child

The mean scores and standard deviations for the sub-scale of attachment to child under the parent domain are presented in Table 5.8. All items for this sub-scale were reversed.

**Table 5.8: Means and Standard Deviations for Attachment to Child (N = 50)**

<b>Attachment to child items</b>	<b>Strongly disagree n (%)</b>	<b>Disagree n (%)</b>	<b>Undecided n (%)</b>	<b>Agree n (%)</b>	<b>Strongly agree n (%)</b>	<b>Mean</b>	<b>SD</b>
Do everything you can for grandchild (reversed)	1 (2)	1 (2)	0	17 (34)	31 (62)	1.48	0.79
Feel close to grandchild (reversed)	0	0	0	7 (14)	43 (86)	1.14	0.35
Enjoy spending time with grandchild (reversed)	0	0	0	7 (14)	43 (86)	1.14	0.35
Grandchild is an important source of love (reversed)	0	0	0	11 (22)	39 (78)	1.22	0.42

From Table 5.8, the items were reverse-scored for this “attachment to child” sub-scale. Low levels of stress were found in this sub-scale. For the item “do everything you can for grandchild”, where 62% ( $n = 31$ ) of the grandparents strongly agreed with this item. , The item of “feel close to grandchild”, 86% ( $n = 43$ ) of the grandparents agree with this item. The majority of the grandparents, 86% ( $n = 43$ ) strongly agreed with the item “enjoy spending time with grandchild” and 78% ( $n = 39$ ) strongly agreed with the item “grandchild is an important source of love”. The high scores of these items showed that the grandparents had a strong attachment to their grandchild.

### 5.3.2.3 Role conflict

The mean scores and standard deviations for the sub-scale of role conflict under the parent domain are presented in Table 5.9. All items for this sub-scale were reversed.

**Table 5.9: Means and Standard Deviations for Role Conflict (N = 50)**

<b>Role conflict items</b>	<b>Strongly disagree n (%)</b>	<b>Disagree n (%)</b>	<b>Undecided n (%)</b>	<b>Agree n (%)</b>	<b>Strongly agree n (%)</b>	<b>Mean</b>	<b>SD</b>
Happy in role as a caregiver (reversed)	1 (2)	2 (4)	1 (2)	13 (26)	33 (66)	1.50	0.89
Satisfied as a grandparent (reversed)	0	0	1 (2)	15 (30)	34 (68)	1.34	0.52

From Table 5.9, the two items of the role conflict sub-scale were reversed scored. For the item of “happy in role as a caregiver” ( $M = 1.50$ ;  $S.D = 0.89$ ) where 66% ( $n = 33$ ) of the grandparents strongly agreed with this item. For the item of “satisfied as a grandparent” ( $M = 1.34$ ;  $S.D = 0.52$ ) where 68% ( $n = 34$ ) of the grandparents strongly agreed with this item.

## 5.4. The Results of the Grandparent’s Well-being (PWBI)

The construct of well-being, measured by the PWBI, was measured by two main domains, namely general well-being and child-related well-being. The domain of general well-being was measured by the general emotional well-being and general physical well-being sub-scales, while the child-related well-being was measured by the child-related emotional and child-related physical well-being sub-scales. Each sub-scale had two positively scored items and two negatively scored items. All items were measured on a four-point Likert-type scale ranging from 1.00 (*you never felt like this*) to 4.00 (*you often felt like this*). The participants were required to reflect on how they felt, either since the beginning of that month, or since the past two weeks. The scoring criteria as devised by Trivette and Dunst (1986) required 8 to be added to the sum of the positively scored items, with the result then subtracted from the sum of the negatively scored items. The result of this would provide the total score for each sub-scale. The sub-scales were then summed to obtain a total score. If two or more items were missing, the sub-scale would not be valid and could not be used. No items were missing in the current study and all items were scored. The sum of the 16 items provides the global measure of well-being, where high scores indicated high levels of well-being. The scores are reported with the grouping of all the positive scores for all four sub-scales (Table 5.10) and all the negative scores for all the four sub-scales (Table 5.11).

### 5.4.1. Positive well-being domain

The mean scores and standard deviations for the positive well-being domain items are presented in Table 5.10. With the scoring of 1.00 indicating “you never feel like this” and 4.00 signifying “you often feel like this”, the positive scores of the items are interpreted in such a way that a high score would indicate higher levels of well-being.

**Table 5.10: Means and Standard Deviations for Positive Well-Being (N = 50)**

Domains	Positive well-being items	Never felt this n (%)	Felt this once in a while n (%)	Sometimes felt this n (%)	Often felt this n (%)	Mean	SD
General							
Emotional	Felt that life is going just great	4 (8)	10 (20)	19 (38)	17 (34)	2.98	0.94
Well-Being	Felt really happy	1 (2)	5 (10)	19 (38)	25 (50)	3.36	0.75
		8 (16)	4 (8)	17 (34)	21 (42)	3.02	1.08

Domains	Positive well-being items	Never felt this n (%)	Felt this once in a while n (%)	Sometimes felt this n (%)	Often felt this n (%)	Mean	SD
General Physical Well-Being	Felt they had energy to get things done (e.g. household chores)						
	Felt in great shape	5 (10)	7 (14)	20 (40)	18 (36)	3.02	0.96
Child-Related Emotional Well-Being	Felt glad about future of grandchild with a disability	1 (2)	4 (8)	15 (30)	30 (60)	3.48	0.74
	Found pleasure in the things grandchild with a disability does	1 (2)	3 (6)	11 (22)	35 (70)	3.60	0.70
Child-Related Physical Well-Being	Felt it is easy to physically take care of grandchild with a disability	4 (8)	7 (14)	12 (24)	27 (54)	3.24	0.98
	Had energy to keep up with grandchild with a disability	2 (4)	5 (10)	15 (30)	28 (56)	3.38	0.83

On the general emotional well-being sub-scale, the grandparents scored the lowest for the item of “felt that life is going just great” ( $M = 3.02$ ;  $S.D = 0.96$ ) where 38% ( $n = 19$ ) of grandparents sometimes felt this. On the other hand, for the sub-scale of child-related emotional well-being, the item of “found pleasure in the things grandchild with a disability does” ( $M = 3.60$ ;  $S.D = 0.70$ ), had 70% ( $n = 35$ ) of the grandparents who reported to often feel this way.

#### 5.4.2. Negative well-being domain

The mean scores and standard deviations for the domain of negative well-being items are presented in Table 5.11. The scoring of 1.00 indicates “you never feel like this” and 4.00 signifies “you often feel like this”, the negative scores of the items are interpreted in such a way that a high score would indicate lower levels of well-being.

**Table 5.11: Means and Standard Deviations for Negative Well-Being (N =50)**

<b>Domains</b>	<b>Negative well-being items</b>	<b>Never felt this n (%)</b>	<b>Felt this once in a while n (%)</b>	<b>Sometimes felt this n (%)</b>	<b>Often felt this n (%)</b>	<b>Mean</b>	<b>SD</b>
General Emotional Well-Being	Felt uneasy or scared without knowing why	10 (20)	9 (18)	5 (10)	26 (52)	2.06	1.24
	Felt down or depressed	7 (14)	16 (32)	4 (8)	23 (46)	2.14	1.16
General Physical Well-Being	Felt unwell or ill	5 (10)	23 (46)	10 (20)	12 (24)	2.42	0.97
	Felt tired or run-down	6 (12)	13 (26)	14 (28)	17 (34)	2.16	1.04
Child-Related Emotional Well-Being	Felt trapped by responsibilities as a caregiver	8 (16)	11 (22)	8 (16)	23 (46)	2.08	1.16
	Felt there is no end to the demands grandchild with a disability makes	8 (16)	13 (26)	4 (8)	25 (50)	2.08	1.19
Child-Related Physical Well-Being	Felt tired or exhausted after caring for grandchild with a disability	3 (6)	16 (32)	10 (20)	21 (42)	2.02	1.00
	Felt like caring for grandchild with a disability puts a strain on you	8 (16)	8 (16)	8 (16)	26 (52)	1.96	1.16

As can be seen in Table 5.11 for the sub-scale of general physical well-being, 46% ( $n = 23$ ) of the grandparents expressed that they “felt unwell or ill” ( $M = 2.42$ ;  $S.D = 0.97$ ) once in a while and for the item of “felt there is no end to the demands grandchild with a disability makes” ( $M = 2.08$ ;  $S.D = 1.19$ ) where 50% ( $n = 25$ ) of the grandparents often felt this.

### 5.5. The Results of the Perceived Need for Types of Support (SFS)

The construct of perceived social support was measured using the SFS to measure the appraisal for the need for types of social supports. The SFS scale was composed of four sub-scales and all items were rated on a four-point Likert-type scale; the scores ranged from 1.00 (*you never need this help*) to 4.00 (*you need this help quite often*). According to the scoring criteria of the SFS (Dunst & Trivette, 1986), the scores for each item of the sub-scales were summed to obtain the sub-scale scores. The sub-scale scores were then added to provide a total summed score from which 60 was subtracted to result in the final score for the SFS; higher scores indicated more support and less need for help (Dunst & Trivette, 1986). However, when looking closer at the item means, it is interpreted that the higher the means, the more the need for that type of support



is evident. The mean scores and standard deviations for the need for the five types of support items are presented in Table 5.12.

**Table 5.12: Means and Standard Deviations for Types of Support Needed (N = 50)**

Types of support needed	Never needed this help n (%)	Needed this help once in a while n (%)	Sometimes needed this help n (%)	Needed this help quite often n (%)	Mean	SD
<b>Emotional support items</b>						
Someone to talk to about things that worry you	8 (16)	15 (30)	10 (20)	17 (34)	2.72	1.11
Someone to talk to for questions about raising grandchild with a disability	10 (20)	13 (26)	14 (28)	13 (26)	2.60	1.09
Someone to encourage you to keep going when things seem hard	9 (18)	10 (20)	16 (32)	15 (30)	2.74	1.08
Someone to relax or laugh with	8 (16)	14 (28)	14 (28)	14 (28)	2.68	1.06
<b>Child support items</b>						
Someone to help take care of grandchild with a disability	20 (40)	10 (20)	6 (12)	14 (28)	2.28	1.10
Someone to accept grandchild with a disability regardless of how he or she acts	13 (26)	11 (22)	7 (14)	19 (38)	2.64	1.18
Someone to do things with grandchild with a disability	15 (30)	7 (14)	14 (28)	14 (28)	2.54	1.20
<b>Financial support items</b>						
Someone to lend money when needed	15 (30)	10 (20)	12 (24)	13 (26)	2.46	1.18
Someone to help with transportation	20 (40)	6 (12)	10 (20)	14 (28)	2.36	1.27
<b>Instrumental support items</b>						
Someone to help with household chores	21 (42)	6 (12)	10 (20)	13 (26)	2.30	1.27
Someone to follow up with SASSA (e.g., grants) or hospital services	27 (54)	6 (12)	9 (18)	8 (16)	1.96	1.18
<b>Agency support item</b>						
Someone to tell you about services for grandchild with a disability or your family	13 (26)	7 (14)	11 (22)	19 (38)	2.72	1.23

From the results in Table 5.12, the domain of emotional support showed the highest mean of 2.72 for the item of “someone to talk to about things that worry you” ( $M = 2.72$ ;  $S.D = 1.11$ ), reported for 34% ( $n = 17$ ) of the grandparents. For the item of “someone to encourage you to keep going when things seem hard” ( $M = 2.74$ ;  $S.D = 1.08$ ), 32% ( $n = 16$ ) of the grandparents said that they sometimes needed this type of help. A high mean was also evident for the item of “someone to tell you about services for grandchild with a disability or your family” ( $M = 2.72$ ;

$S.D= 1.23$ ), where 38% ( $n = 19$ ) of the grandparents indicated that they often needed this form of help. The need for “someone to follow up with SASSA” ( $M = 1.96$ ;  $S.D = 1.18$ ) was the lowest rated, with 54% ( $n = 27$ ) of the grandparents never needing this help.

In the domain of child-related support, 40% ( $n = 20$ ) of the grandparents never needed help in the form of “someone to help take care of grandchild with a disability” ( $M = 2.28$ ;  $S.D = 1.10$ ). With the item of “someone to accept grandchild with a disability regardless of how he or she acts” ( $M= 2.64$ ;  $S.D= 1.18$ ), 38% ( $n = 19$ ) of the grandparents reported that they needed this type of help quite often. With the item of “someone to do things with grandchild with a disability” ( $M = 2.54$ ;  $S.D = 1.20$ ), 30% ( $n = 15$ ) of the grandparents said they never needed this type of help. Under the financial support domain items, the item of “someone to lend money when needed” ( $M = 2.46$ ;  $S.D = 1.18$ ), 30% ( $n = 15$ ) of the grandparents reported to never need this type of help. With “someone to help with transportation” ( $M = 2.36$ ;  $S.D = 1.27$ ), 40% ( $n = 20$ ) never needed this type of help. In terms of the instrumental support items, 42% ( $n = 21$ ) of the grandparents said they never needed “someone to help with household chores”.

## **5.6. Relationships between the PSS, PWBI and SFS**

The exclusion of the FSS led to the re-evaluation of the hypotheses that had been initially set out for the study. The relationship between stress, well-being and the perceived needs for types of support (measured by the SFS) was therefore considered. It was consequently hypothesised that:

- i) There will be an inverse relationship between perceived needs for types of support and the stress of the grandparent; that is, the greater the perceived need for types of support, the lower the levels of stress;
- ii) There will be a positive relationship between perceived needs for types of support and the well-being of the grandparent, where the higher the perceived need for types of support, the higher the well-being of the grandparent;
- iii) There will be an inverse relationship between stress and the well-being of the grandparent, where the higher the stress, the lower the well-being of the grandparents;

- iv) Perceived need for types of support will have a mediating effect on the relationship of stress and well-being of the grandparents;
- v) Perceived need for types of support will have a moderating effect on the relationship of stress and well-being of the grandparents;
- vi) The type of grandparent, their age, their monthly household income and their perceptions of their financial status will have an effect on the grandparents' stress, well-being and perceived need for types of support.

The correlation between the three measures of the PSS, the PWBI and the FSS was analysed through a series of linear regressions to identify the nature of the relationships which exist between the three constructs (Kline, 2011). For the linear regression, the Pearson  $r$  value was considered to show the linear relationship between the three sets of data for caregiving stress (PSS), well-being (PWBI) and the perceived need for types of support (SFS). These results are displayed in Table 5.13.

**Table 5.13: Correlation Matrix of PSS, PWBI and SFS**

Measures	PSS	PWBI	SFS
PSS	1	-	-
PWBI	-0.52	1	-
SFS	-0.54	0.62	1

In line with the hypothesis posed, there was a significant inverse correlation between the SFS and PSS ( $r = -0.54$ ;  $p < 0.001$ ), where the greater the perceived need for types of support, the lower the stress of the grandparent.

Also in line with the set out hypothesis, there was a significant positive correlation between the SFS and the PWBI ( $r = 0.62$ ;  $p < 0.01$ ), where the higher the perceived need for types of support, the higher the well-being of the grandparent.

A significant negative correlation was found between PSS and the PWBI ( $r = -0.52$ ;  $p < .001$ ), where higher levels of stress result in lower levels of well-being. This result was in line with the hypothesis initially set out.

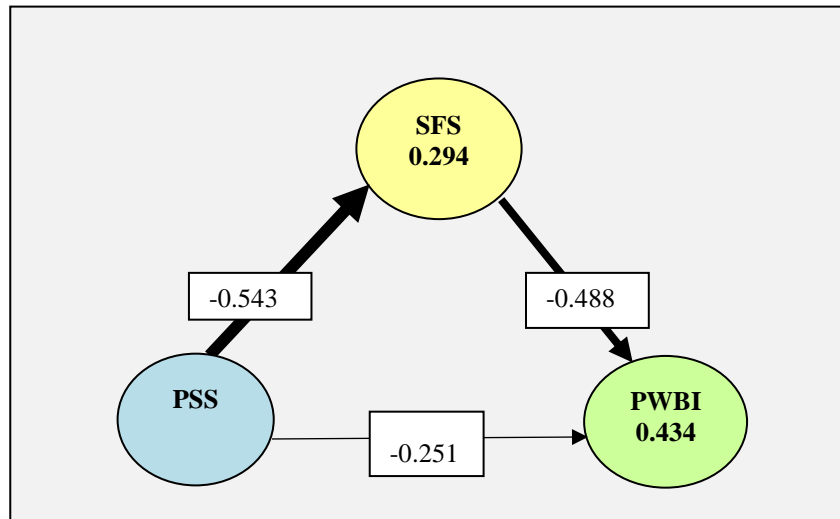
## **5.7. Mediating and Moderating Effects of Perceived Social Support on Stress and Well-being**

The next step was to analyse and describe the causal pathways between the three variables, that is, the mediating and moderating effects of perceived need for types of support (SFS) on the relationship of stress (PSS) and well-being (PWBI). This analysis provided insight into the mechanisms of how SFS may mediate or buffer the effects of stress on well-being of the grandparents. Therefore, the mediating and moderating effects of the SFS on the relationship of the PSS and PWBI were analysed.

### **5.7.1. Mediating effect of the SFS**

The Sobel test was used to detect the presence of any mediation type of effect of the SFS on the relationship of the PSS and the PWBI (Kline, 2011). Three different outcomes are expected with mediation, namely either full mediation, partial mediation or no mediation. Full mediation would indicate that there is an insignificant relationship between the PSS and the PWBI with all the causal effects going through the mediator (SFS). Partial mediation would mean that there is some mediation via the mediator (SFS), but there is also some direct effect of the PSS on the PWBI. No mediation would indicate that there is a full to highly significant relationship between the PSS and the PWBI with no mediating effect of the mediator (SFS).

Since the Sobel test provides information about the presence of mediating effects only, Partial Least Squares Structural Equations Model (PLS SEM) was further used to provide more information regarding the degree of mediations between the constructs (Kline, 2011). As initially postulated, there was an effect between the PSS, the PWBI and the SFS, and thus regression coefficients were estimated to indicate how significant the mediating effect was. Figure 5.1 illustrates the degree of mediation between the SFS, PSS and the PWBI as displayed in Table 5.14.



**Figure 5.1: Mediating Effects of Need for Types of Support on Stress and Well-being**

Figure 5.1 shows that there is no significant relationship between PSS on the PWBI ( $p = 0.05$ ) compared to the significant and strong effect between SFS and PWBI ( $p < 0.01$ ). Furthermore, a significant direct effect of PSS on SFS ( $p < 0.01$ ) and the strong significant effect of the mediating effect of the SFS on the PWBI ( $p < 0.01$ ). The insignificant relationship between PSS on PWBI shows that SFS has a strong mediating effect on PSS and PWBI. Therefore, it is concluded that a full mediator effect of perceived need for types of support exists between stress and well-being.

**Table 5.14: Path Coefficients (CI) between PSS, PWBI and SFS**

	From	To	Original sample	Significant from CI	p-value from T-test
PSS → PWBI	PSS	PWBI	-0.251	no	0.05
PSS → SFS	PSS	SFS	0.543	yes	0.00*
SFS → PWBI	SFS	PWBI	-0.488	yes	0.00*

$p < 0.01$ \*

### 5.7.2. Moderating effects of perceived social support

The analysis of the moderating effect of the SFS resulted in no moderating effect ( $p = 0.77$ ) of the SFS on the PSS and PWBI as presented in Table 5.15.

**Table 5.15: Moderation Effects of SFS and FSS**

Independent Variable	Moderator	Dependent Variable	Interaction Coefficient	R <sup>2</sup> with Interaction	R <sup>2</sup> Independent Variable Only	R <sup>2</sup> Change	p-value
PSS Total	SFS Total	PWBI Total	-0.49	0.44	0.43	0	0.77

Therefore, because the SFS did not change the strength of the relationship of PSS and PWBI, there was no causal effect on the two constructs, which indicated no moderating effect of the perceived need for types of support on stress and well-being.

## 5.8. Correlations between the Demographic Variables and PSS, PWBI and SFS

Given the results of the relationships found between stress, well-being and perceived needs for types of support, it was important to identify whether the contextual factors were also influencing the three constructs (PSS, PWBI and SFS). It was hypothesised that the grandparent's age and financial situation may have an influence on the grandparents' stress, well-being and their perceived social support. Therefore, correlations were carried out between the three constructs and the reported type of grandparent, their age, their monthly household income and their perceptions of their financial status.

### 5.8.1. Type of grandparent caregiver

The correlations between the type of grandparent – that is, either a co-parenting or a sole-parenting grandparent – and the PSS, PWBI and SFS are presented in Table 5.16.

**Table 5.16: Correlations between Type of Grandparent and PSS, PWBI and SFS at 95% Confidence Interval (N = 50)**

Type of grandparent and measure	N = 50	Mean	SD	F	P
<b>PSS</b>					
co-parent	30	46.63	13.16	3.59	0.06*
sole parenting	20	53.35	10.81		
<b>PWBI</b>					
co-parent	30	41.47	8.44	0.10	0.75
sole parenting	20	40.70	7.97		
<b>SFS</b>					
co-parent	30	30.80	8.90	0.62	0.44
sole parenting	20	28.80	8.65		

*p* < 0.10\*

The results show that there was a statistically significant correlation between the PSS and the type of grandparent ( $F = 3.59$ ;  $p < 0.10$ ). There was no statistically significant correlation found between the PWBI of grandparents and the type of grandparents ( $F = 0.10$ ;  $p = 0.75$ ) and no statistically significant correlation between the SFS and the type of grandparents ( $F = 0.62$ ;  $p = 0.44$ ).

The correlations between age and the grandparent's socio-economic status are presented in Table 5.17.

**Table 5.17: Correlations between Demographic Variables and PSS, PWBI and SFS at 95% Confidence Interval (N = 50)**

Grandparent characteristic	PSS (caregiving stress)		PWBI (well-being)		SFS (perceived need for support)	
	r	p-value	r	p-value	r	p-value
Age	0.28	0.05*	-0.27	0.06*	0.17	0.24
Monthly household income						
Number working and contributing	-0.46	<0.01**	0.15	0.30	-0.27	0.06*
Household income	-0.38	<0.01**	0.31	0.03**	-0.23	0.11

\* $p < .10$  \*\* $p < .05$

### 5.8.2. Age

The age of the grandparents who took part in this study ranged from 39.0 years to 74.0 years ( $M = 55.06$ ;  $SD = 8.70$ ). A statistically significant positive correlation ( $r = 0.28$ ;  $p = 0.05$ ) is indicated between the PSS and age of the grandparent, which indicated that the older grandparents reported higher levels of caregiving stress. A statistically significant negative correlation ( $r = -0.27$ ;  $p = 0.06$ ) was also found between age and the PWBI, where the older grandparents reported lower levels of well-being.

### 5.8.3. Monthly household income

The reported household income consisted of the number of people working and contributing to the household income.

### 5.8.3.1 Number working and contributing

The correlations showed that between the number of people working and the PSS, a moderate and statistically significant negative correlation ( $r = -0.46$ ;  $p < 0.05$ ) was found, indicating that there were lower levels of stress with a higher number of people working in the household. A statistically significant correlation ( $r = -0.27$ ;  $p < 0.10$ ) was found between the number of people working and the FSS, which indicated that the higher the number of people working in the household, the lower the level of perceived need for support.

### 5.8.3.2 Household income

There was a statistically significant negative correlation ( $r = -0.3$ ;  $p < 0.05$ ) between the PSS and the household income, which indicated that the grandparents had higher levels of stress with lower levels of household income. A statistically significant and positive correlation ( $r = 0.31$ ;  $p < 0.05$ ) was present between the household income and PWBI, which implied that the grandparents experienced high levels of well-being with greater household income.

### 5.8.3.3 Perceived financial situation

To analyse the correlations between the perceived financial situation with the PSS, PWBI and SFS, Kruskal-Wallis one-way ANOVA was used (Table 5.18). Within the sample of the grandparents ( $N = 50$ ), 62% ( $n = 31$ ) of them perceived their financial situation as a struggle as they did not have enough to get by every month. Twenty per cent ( $n = 10$ ; 20%) reported that they just get by every month and 18% ( $n = 9$ ) reported that they had money left at the end of the month. The correlations between perceived financial situations and the PSS, PWBI and SFS are shown in Table 5.18.



**Table 5.18: Correlations between Financial Situation and PSS, PWBI and SFS at 95% Confidence Interval (N = 50)**

Financial situation	N = 50	Mean	SD	F	P
<b>PSS</b>					
struggling and not enough	31	54.65	10.92	11.35	<0.01*
just get by at the end of the month	10	37.40	8.69		
have money left at the end of the month	9	44.22	11.10		
<b>PWBI</b>					
struggling and not enough	31	39.42	7.44	1.94	0.15
just get by at the end of the month	10	44.40	9.79		
have money left at the end of the month	9	43.56	7.94		
<b>SFS</b>					
struggling and not enough	31	32.68	8.52	4.34	0.02*
just get by at the end of the month	10	25.30	8.79		
have money left at the end of the month	9	26.00	6.18		

\* $p < 0.05$

As seen in Table 5.18, there was a statistically significant correlation between PSS and the perceived financial situation of the three groups ( $F = 11.35$ ;  $p < 0.05$ ), which indicated that the grandparents had stress associated with their perception of their financial situation. Finally, a statistically significant correlation was found between the perceived need for types of support and perceived financial situation ( $F = 4.34$ ;  $p < 0.05$ ), where the grandparents reported that they required support associated with their perceived financial income.

## 5.9. Summary

This chapter presented the results of the data collected in this study. Details were provided regarding the reliability of the measures used, and the rationale presented for the exclusion of one measure from further analysis. Further details of the results of the three measures were provided. The correlations between the three measures as well as the mediating and moderating effects of the SFS on the PSS and PWBI were presented. The chapter concluded with the correlations between the three measures and the reported demographic variables of type of grandparent, their age, their monthly household income and their perceptions of their financial status. Next, in Chapter 6, these results will be discussed.

## Chapter 6: Discussion

### 6.1. Introduction

This chapter provides a discussion of the results in relation to the aim and sub-aims of the study. The main aim of the study was to explore the relationship between perceived social support, stress and well-being of grandparents raising their grandchild with a congenital disability. The results of these relationships are interpreted and discussed against past literature and research. Further information from the results of each of the three measures analysed is integrated within the discussion of these relationships. The findings of the mediating effects of perceived social support are also discussed in the context of parenting grandparents.

### 6.2. Background of Parenting Grandparents of the Study

Two types of grandparents were included in the current study, namely sole-parenting grandparents who are raising their grandchild with a congenital disability in the absence of the parent of the grandchild, and co-parenting grandparents who are raising their grandchild with a congenital disability with either of the biological parents. Both types of grandparents fulfilled the daily role of parenting and caring for their grandchild with a congenital disability while living in the same household. As shown in previous research within the Western Cape (Samuels, 2013), the trend of older persons living in a large extended family in one household within the Western Cape (Schatz et al., 2015; Statistics South Africa & Lehola, 2014a) was reflected in the current study, where 60% of the grandparents were co-parenting grandparents, and 40% were sole-parenting grandparents (Table 4.2). Although the current study was not comparative in nature, it was essential to include as many parenting grandparents as possible to have a more comprehensive understanding of the current situation of the grandparents who are actively raising their grandchild with a congenital disability.

The research aimed to explore the relationships between perceived social support, stress and the well-being of the parenting grandparents. The study was driven by the need to understand how perceived social support can function to support the well-being of the grandparents so that they can provide the optimum quality of parenting and care when raising their grandchild with a congenital disability (Guralnick, 2017; Skok et al., 2006). Furthermore, the indications from past

literature further justified the need for this research. There was a lack of research and understanding of the relationship between the combinations of the three constructs of perceived social support, stress and well-being in the context of grandparents raising their grandchild with a congenital disability.

### **6.3. The Reliability and Validity of the Measures Used**

As previously discussed in section 2.7 of Chapter 2, perceived social support is a dimension of the main construct of social support (Trivette, Deal, & Dunst, 1986). In the current study, perceived social support was measured first by identifying the perceived needs for types of support of parenting grandparents, using the SFS (Dunst & Trivette, 1986), followed by the perceived helpfulness of the available supports using the FSS (Dunst, Trivette, & Jenkins, 1984). The stress of the grandparents was measured using the PSS (Berry & Jones, 1995), and their well-being was measured by the PWBI (Trivette & Dunst, 1986). These four measures have been devised internationally with reported high scores of reliability in a range of studies. However, these measures were yet to be validated in the South African context. In being mindful of the risks of applying measures that have not been validated in the South African context (Marfo & Pence, 2009), care was taken when adapting the measure to the current context. The back-translation framework by Brislin (1986) ensured that the measures were culturally and linguistically equivalent to the South African and the Western Cape context, while still preserving the original intended concepts that were required to be measured. The current study contributes to the validation of the use of the PSS, PWBI and the SFS in the South African context, where they were found to have adequate internal consistencies in measuring the essential facets of stress, well-being and perceived needs for types of support. However, of the four measures, the FSS showed the lowest internal consistency for its sub-scales, between 0.07 to 0.26 (Kline, 2011), after the adaptations had been made, which led to the exclusion of this measure. As a result, the relationships of perceived social support with stress and well-being were analysed in terms of the grandparents' perceived needs for types of support only.

It has been suggested that the reliability of a measure is determined by the number of items per sub-scale (Kimberlin & Winterstein, 2008), where poor reliability of the measure indicates the need for an increase in related items for the sub-scale (Tsang, Royse, & Terkawi, 2017). The small number of items in the sub-scales of the FSS may account for its poor reliability, where

some sub-scales contain fewer than five items. Furthermore, according to Boynton and Greenhalgh (2004), the varied reliability of a measure from one context to another is most often determined by the differences in the participants of the study rather than the inconsistencies of how the items are comprehended or how the items are being interpreted. This makes it crucial to devise measures specific to the current African or South African population itself (Marfo & Pence, 2009). Furthermore, according to Boynton and Greenhalgh (2004), the application of measures that contain items which are devised at a certain previous time period may hold different meanings in the current time period. Since the FSS was devised in 1984, it may be crucial to use more recent measures. The exclusion of the FSS therefore shows that even if a measure has been tested or used in a great number of published studies which have been peer-reviewed (Fordham, Gibson, & Bowes, 2011; Hanley, Tasse, Aman, & Pace, 1998; Kresak & Gallagher, 2014; Littlewood, Swanke, Strozier, & Kondrat, 2012; Whitley, Kelley, & Lamis, 2016), it does not imply that this same measure will hold its validity and reliability in the context of this study (Boynton & Greenhalgh, 2004).

#### **6.4. Stress of Parenting Grandparents**

The construct of stress was measured using the PSS. The stress was measured by the degree to which the grandparent agreed or disagreed with a range of statements related to their grandchild and to their parenting and caregiving roles. The child domain considered the levels of grandparent stress in relation to the demands of caregiving and the behaviours of the grandchild, while the parent domain related to the sense of self-competence of the grandparent, their attachment to the grandchild and the role conflict experienced by the grandparents.

The grandparents in the current study agreed that the demands of caregiving were most stressful due to the amount of time and energy they spent as parents and that they had little control over their own life. This result was similar to previous research (Gallagher, Kresak, & Rhodes, 2010; Hillman & Anderson, 2019; Kresak, Gallagher, & Kelley, 2014), where the role of raising a grandchild with a disability is challenging for the grandparents. As identified by McCallion, Janicki and Kolomer (2004), the lack of time for themselves and the increased energy as part of caregiving may contribute to the limitation of the grandparent's access and participation to much-needed social circles and support groups. The increased daily needs of their grandchild specific to the daily care routines, which are already a source of stress for the grandparents, may

in time become more strenuous as the grandchild grows or ages (Gardiner, Miller, & Lach, 2018; Kim & Chung, 2016).

The grandparents also indicated that raising a grandchild with a disability was a financial burden; in the current study, 60% of the grandparents agreed or strongly agreed with this statement. This has been highlighted as a common feeling experienced by grandparents, and parents alike, in the literature related to raising a child with a disability (Brown et al., 2017; Collins et al., 2017; Hillman & Anderson, 2019; Kresak et al., 2014; Wigren & Hansen, 2003). As identified by Brown et al. (2017), grandparents raising their grandchild with a disability in a poorer context and with financial strains may experience limitations due to the required financial costs of providing for the grandchild's daily necessary needs. They may also not be able to adapt their home situation for the grandchild's physical needs. However, in the current study, the financial constraints experienced by the grandparents was further highlighted by the significant relationship between stress and the number of employed people in the household, the overall household income as well as their perceptions of their financial income. The significant relationship between these three demographic variables further indicated that the grandparents were struggling to provide for their grandchild (Brown et al., 2017; Gallagher et al., 2010).

In spite of the perceived challenges of the grandparent's ability to provide for their grandchild financially, the majority of grandparents in this study did not indicate resentment towards their parenting responsibility, as they mostly disagreed or strongly disagreed with the idea of not taking on this role again if they had the choice to do so. This view is contrary to the past literature (Mitchell, 2007; Yang et al., 2018). In this study, grandparents' lack of resentment for being a parent again may be reflective of their understanding that within extended family systems, it is culturally and socially expected of them to step into the parenting role, as previously identified in South African-based studies (Dolbin-Macnab et al., 2016; Njororai & Njororai, 2013; Schatz et al., 2015). However, the resentment of being a parent in the challenging contextual environment may have also gone undetected due to the interview format of the current study; grandparents may have felt reluctant to display their resentment when confronted with such questions (Noy & Findler, 2016).

In the current study, the TQQ screening tool was used to identify the symptoms of the grandchild's disability (Durkin et al., 1995; Kromberg et al., 2008; Zaman et al., 1990). The majority of the grandchildren 70% (n = 35) had a reported language delay, while 86% (n = 43) had an intellectual delay compared to their age-equal peers. With these various disability symptoms, the grandparents showed strong agreement that their child's behaviour was stressful to them. Disability-related behaviours of grandchildren have been a recurring theme across the literature specific to this population of parenting grandparents (Gallagher et al., 2010; Hillman & Anderson, 2019; Kresak & Gallagher, 2014), which was also indicated in the current study. Previous findings (Gallagher et al., 2010; Gordon, 2018; Hillman & Anderson, 2019) have based this source of stress on the complexity of behaviour due to the child's disability. In these various studies it was found that grandparents expressed concern over the aggression and other physical outbursts which their grandchild may have had (Gordon, 2018; Hillman & Anderson, 2019). As explained by Guralnick (2013), the interactions between a parent and a child are based on the foundation of the cultural and attitudes of the parent, which have been passed on from generation to generation. It can be inferred that the presence of a disability requires an entire change in terms of the grandparents' way of interacting with their grandchild as well as a change in how they understand their grandchild's disability. The literature (Miller et al., 2012) has suggested that grandparents may experience heightened levels of stress when having to interact with their grandchild with a disability. That is, grandparents have may find it challenging to re-adjust how they interact with their grandchild with communication and intellectual disabilities (Miller et al., 2012). For parenting grandparents, the challenges of accommodating for their grandchild's communication difficulties, poor sleeping habits, moodiness, sensory processing disorders, learning difficulties or high impulsivity infer the need for better empowerment of the grandparents (Gallagher et al., 2010; Gordon, 2018; Hillman & Anderson, 2019). The empowerment of parenting grandparents needs to be information-specific, which contributes to the grandparent's understanding and knowledge around the management of their grandchild's disability with the aim of reducing the stress which they may experience during interactions with their grandchild (Woodbridge, Buys, & Miller, 2009). As shown by McCallion et al. (2004), such empowerment can potentially improve the grandparent's self-confidence as a parent, and their family patterns of interaction, namely the grandparent-child transaction with positive

developmental outcomes related to the grandchild's social and cognitive competence (Guralnick, 2013).

However, the concept of child behaviour in the current study also showed a contradiction. Despite the behaviour being stressful to the grandparents, the majority of the grandparents also strongly agreed that they found their grandchild enjoyable, with some studies showing similar perspectives (Gardner et al., 2004; Hillman & Anderson, 2019). It is possible to infer from the results of the current study that these child-related areas may be a source of stress for the grandparent, especially if the grandchild's disability is more severe to profound (Isa et al., 2016). Furthermore, the child's behaviour has been identified as a higher source of stress when the grandchild is older and physically bigger (Gordon, 2018). There is also an indication in the literature that the satisfaction of raising a grandchild with a disability may decrease as the physical strains of daily caregiving activities become more pronounced (Kim & Chung, 2016). In the current study, the grandchildren were under the age of 9 years, which meant that their behaviour was stressful. However, based on the literature, there is a high risk that the child's behaviour may become more stressful as the child ages (Kim & Chung, 2016; Samuel et al., 2017).

The sense of self-competence of the parenting grandparents raising their grandchild with a disability was found to be a source of stress. The majority agreed or strongly agreed that they felt they were not doing enough for their grandchild. It is possible that the grandparent's uncertainty around their grandchild's disability can be associated with this high level of stress (Gallagher et al., 2010). The need for information specific to understanding their grandchild's disability has been further highlighted in literature, as grandparents may experience feelings of worry if they are unsure about how they can better help their grandchild, especially in terms of what intervention would be best for their grandchild (Hillman & Anderson, 2019). However, these results may also indicate that the grandparents could be experiencing threats to their self-efficacy as parents. As shown in previous literature (Ben Shlomo & Taubman-Ben-Ari, 2012), grandparents who experienced low self-confidence due to their self-efficacy indicated low levels of empowerment towards their role as parents of a child with a disability, which may be the case for the grandparents in the current study. The majority of grandparents also overwhelmingly agreed or strongly agreed that, because their grandchild was in their care, they had a better view

of the future for their grandchild. This was expressed especially by the grandparents in the study who reported to be raising their grandchild because they had a strained relationship with the parent of the child (Gordon, 2018).

The grandparents reported a positive relationship with their grandchild (Table 5.8 in Chapter 5), indicating that the majority of the grandparents agreed that they did everything they could for their grandchild, and that they experienced closeness with their grandchild. The grandparents also reported enjoying the time they spent with their grandchild and strongly agreed that their grandchild was an important source of affection to them. Once more, this result indicated a strong bond and attachment experienced by grandparents in this parenting role, in spite of the challenges they face (Hillman & Anderson, 2019). This has been highlighted in the literature as well, where grandparents parenting their grandchild with a disability have reported a strong and unique bond with their grandchild (Gardner et al., 2004; Woodbridge, Buys, & Miller, 2011).

Finally, the stress of the grandparents was measured in terms of their role conflict; it has been identified in literature that grandparents may experience strains due to the social roles they are expected to fulfil, leading to stress and physical exhaustion (Yang et al., 2018). More specifically, these role conflicts have been highlighted to surface due to the sociocultural expectations that are attached to the grandparent's responsibility of parenting and caring for their grandchild with a congenital disability (Kresak & Gallagher, 2014). The presence of role conflict has been noted especially for grandparents who are co-parenting and who experienced family conflicts with their grandchild's parent (Yang et al., 2018). These role conflicts are indicated to be a source of stress for the grandparents, with accumulation over time (Pandialagappan & Ibrahim, 2018). However, in the current study, the low score of stress from the domain of role conflict indicated that 66% of the grandparents strongly agreed they were happy in their role as a parent, and 68% of the grandparents strongly agreed to being satisfied as a grandparent for their grandchild. It is possible to infer that the grandparents either had a harmonious relationship with their grandchild's parent or, as indicated by Bundy-Fazioli, Fruhauf and Miller (2013), the grandparents may have learnt to set emotional boundaries to protect their roles as a parent and grandparent. This is especially so for those who had conflicting relationships with the parent of the grandchild.



## 6.5. Well-being of Grandparents

The well-being of the grandparents in the current study was measured using items of both positive and negative affect, relating to the general emotional and physical well-being of the grandparent and the child-related emotional and physical well-being. The grandparents provided their responses in terms of how often they had felt a specific emotion or physical feeling.

In terms of the positive well-being items, the grandparents indicated a reasonably positive general emotional well-being for the item of “feeling that life is going great”, which indicated that the grandparents perceived that their life was generally “great”. This result is contrary to literature where, in their comparative study, Kresak et al. (2014) found that grandparents raising their grandchild with a disability reported lower life satisfaction compared to grandparents raising their grandchild without a disability. Given the influence of the environmental risk factors on the well-being of the caregiver as identified in the literature (Guralnick, 2015), the positive life perception of the grandparents differed from the identified low life satisfaction found in grandparents who experience low levels of financial well-being (Kresak et al., 2014). This perception of general emotional well-being of the current study’s grandparents was also contradictory to the relationship identified between the well-being measure and the reported financial household income (Table 5.17). There was, instead, an indication that grandparents may have reduced levels of well-being if they had lower household income.

The grandparents in the current study also reported higher levels of child-related emotional well-being in relation to finding pleasure and happiness in the things their grandchild did. This was supported by Hillman and Anderson (2019), who found that the celebration of their grandchild’s milestones was an important emotional coping mechanism for grandparents amidst the various stressors they experienced when raising their grandchild with a disability. However, for grandparents to be able to celebrate these milestones, it is important for them to have knowledge regarding the prognosis of their grandchild so that they may adjust their expectations (Gallagher et al., 2010).

In terms of the negative well-being items, the grandparents in the current study did not report high levels of strain in terms of their physical well-being related to being able to do their daily chores or feeling tired. This may be because grandparents in the current study were younger than

expected; the mean age was 55 years ( $S.D = 8.70$ ). However, the strong relationship found between the age and well-being of the grandparents (Table 5.17) shows that older grandparents in this sample might be at risk for lower levels of well-being, which is in line with the past literature (Samuel et al., 2017). Although the grandparents in the current study were young on average, a large number (68%) reported having some form of medical condition. This again is indicative of the possible health strain as reported in the literature (Brown et al., 2017; Gallagher et al., 2010; Kresak et al., 2014; Muliira & Musil, 2010) where grandparents raising a grandchild with a disability are at a heightened risk of developing some form of medical condition due to the stress related to raising their grandchild.

The majority of grandparents did not present low levels of well-being for the negative items related to the child-related physical well-being; their scores indicated that they were physically able to take care of the grandchild and had the energy to keep up with the grandchild. It is possible that these parenting grandparents were able to keep up with their grandchild because the sample in this study is a relatively young cohort. This is in line with the literature (Luo et al., 2012; Whitley, Kelley, et al., 2016) which has found that younger grandparents compared to older grandparents usually express lower levels of physical exhaustion. However, as further indicated in the literature as well as in this study, there may be a risk that the child-related physical well-being may reduce in time as both grandchild and grandparent age (Kim & Chung, 2016; Mhaka-Mutepfa, Cumming, & Mpofu, 2014). Kim and Chung (2016) also show that the close relationship between the grandparent and the grandchild may mediate the stress that can exist between the caregiver and the child. The close attachment and emotional closeness reflected in the grandparents' responses on the child-related positive well-being items in the current study may provide a further important coping mechanism for the grandparents (Hillman & Anderson, 2019; Kim & Chung, 2016).

As highlighted by past studies (Janicki et al., 2000; Noy & Findler, 2016), grandparents have been found to report positive physical health so that they are seen as being capable of fulfilling their parenting and caregiving role. Therefore, grandparents may guard against being perceived as being unable to raise their grandchild. It is possible that this may have been the case in the current study due to the contradicting reported high scores on the physical and emotional well-

being of the grandparents in contrast with the disclosure of medical conditions (Janicki et al., 2000; Noy & Findler, 2016).

## **6.6. Perceived Social Support (Needs for Support) of Grandparents**

The SFS measured five types of support which could be needed by the grandparents raising their grandchild with a congenital disability, namely emotional support, child support, financial support, instrumental support and agency (services) support. Past studies (Gallagher et al., 2010; Gardner et al., 2004; Hillman & Anderson, 2019; Kresak et al., 2014; McCallion, Janicki, & Kolomer, 2004) have shown that grandparents have specific and unique needs, mostly due to their heightened risk of social isolation and due to threats to their feelings of competence as parents when raising their grandchild with a congenital disability.

One of the most needed types of support for the grandparents in the study was that of emotional support in terms of needing someone to encourage them when things became challenging and to have someone to talk to about things that worried them. The literature has shown that grandparents require such emotional support when raising their grandchild with a disability, often due to the challenges, such as communication difficulties and behaviour issues, they face with the disability of their grandchild (Gallagher et al., 2010; Gardner, Scherman, Efthimiadis, & Schultz, 2004; Kresak & Gallagher, 2014). Generally, the grandparents in the current study also reported that they needed the emotional support to discuss their worries or to encourage them when they were tired. These expressions of need for emotional support are indicative that the grandparents in this study may also experience some degree of social isolation, which the literature on grandparents raising a grandchild with a disability has also highlighted (Brown et al., 2017; Gallagher et al., 2010; Kresak et al., 2014). Sources of such support have been mostly in the form of informal supports, such as family and friends (Gardner et al., 2004; Hillman & Anderson, 2019; Kresak et al., 2014), although these grandparents have been shown to have less access to these informal supports when raising their grandchild with a disability (Kresak et al., 2014). The literature (Brown et al., 2017; McCallion et al., 2004) has also indicated that grandparents may lack the important emotional support from support groups. Due to the high need for emotional support, it is possible that the grandparents in the current study may not have had access to such grandparent support groups. The emotional support provided by their informal network and by support groups has been identified in the literature as a crucial source of coping

and improvement in the grandparents' parenting abilities as well as in lowered risks to depression (McCallion et al., 2004).

The grandparents also expressed a need for agency support in terms of what services were available for their grandchild with a disability. The community resource flyers that were provided to the grandparents at the end of the interview in the current study afforded the grandparents with such information. From the literature, agency support has also been identified as an important priority need for this population of grandparents (Gallagher et al., 2010; Hillman & Anderson, 2019; McCallion et al., 2004). The importance of this form of formal support has been linked to increasing the grandparent's knowledge and addressing their specific needs related to their grandchild's disability (Kresak et al., 2014; McCallion et al., 2004). In the current study, as part of their sense of self-competence (Table 5.7), the vast majority (86%) of grandparents agreed or strongly agreed that they worried about not doing enough for their grandchild. Therefore, it is possible that the grandparents showed high levels of stress due to being overwhelmed by their worry of about not doing enough for their grandchild with a disability. This finding is also echoed in the literature, where intervention type studies (Kresak et al., 2014; McCallion et al., 2004) showed that increasing the knowledge of grandparents regarding their grandchild's disability and their disability-related needs can increase the grandparent's self-competence because they are better able to engage with and manage their grandchild's disability-related behaviour. In the current study, the grandparents further indicated a strong need for information regarding what services are available for their grandchild. By knowing what services are available, grandparents may be more willing to seek the needed intervention for their grandchild (Hillman & Anderson, 2019; Tang, Jang, & Copeland, 2015). The indicated stress levels associated with the need for information specific to the grandchild's disability may further confirm that the need for professional and intervention specific support is of a high priority for these grandparents.

In the current study, the lowest need identified was for instrumental support specific to the need for help with following up with SASSA (social grants agency) or hospital services, due to the fact that the majority of the participants, 98% (n = 49), with the exception of one grandmother, reported that they were already accessing their social grant and therefore did not need support with this. In certain cases, the parent of the child had also already completed the procedures to

have access to these grants. The low indication of the need for instrumental support in the current study is a positive indication, as it has been suggested in the literature that grandparents may experience stress around having to navigate through the system when seeking financial support (Ardington et al., 2010; Schatz et al., 2015). However, given the significant relationship found in this study between the grandparent's perception of their financial status and stress (Table 5.18), it is possible to infer that these social grants are still insufficient for the expenses related to raising a grandchild with a disability (Ardington et al., 2010; Schatz et al., 2015).

### **6.7. Relationships between Perceived Social Support, Stress and Well-being**

The hypotheses for the current study were based on the literature of parents raising children with a disability (Lee, 2013; Sipal & Sayin, 2013; Skok et al., 2006; Vanegas & Abdelrahim, 2016). No studies in the review of the grandparent literature had considered the relationship between the three constructs of perceived social support, stress and well-being of grandparents raising their grandchild with a congenital disability. The aforementioned studies found that the combination of perceived social support, stress and well-being of the parent raising their child with a disability had indicated that the parent's well-being was influenced by stress as well as by perceived social support (Sipal & Sayin, 2013; Skok et al., 2006). The further motivation to explore the relationship between these three constructs was based on the fact that the well-being of the parent, or grandparent, is a critical family characteristic factor in ensuring that the child receives the optimal level of care suited for their developmental outcomes amidst their disability (Guralnick, 2013). Perceived social support has been shown to have a positive influence on stress (Kresak & Gallagher, 2014) and well-being (Brown et al., 2017; McCallion et al., 2004) in separate conditions for grandparents raising their grandchild with a disability. It was therefore important to identify whether perceived social support could also function positively to support grandparents raising their grandchild with a congenital disability in the current study. Three hypotheses were posed to better understand the relationship between perceived social support, stress and well-being of the grandparents in this study.

Firstly, from the literature which suggests that perceived social support may reduce stress of parents (Brown et al., 2017; McCallion et al., 2004), it was hypothesised that there would be an inverse relationship between perceived social support and the stress of grandparents raising their grandchild with a congenital disability. From the results of the study, the re-evaluated hypothesis

(section 5.6 in Chapter 5) was found to be supported. When the perceived need for types of support increased, there were indications of lower levels of stress, which is consistent with other studies (Brown et al., 2017; Demirtepe-Saygili & Bozo, 2011; McCallion et al., 2004). This finding suggests that the process of identifying what types of support are needed and perceived as a priority to the grandparent offers the potential of decreasing their levels of stress (Demirtepe-Saygili & Bozo, 2011). The process of needs identification has been supported and advocated by Trivette et al. (1986), who highlight that intervention is crucial to empower caregivers to problem-focus by identifying their needs and to then mobilise the parent's environment and community to ensure that these needs are met. However, at the heart of perceived needs for support is the prioritisation of what needs are the most important to the grandparent, such as emotional support or informational support. This can then be matched to the actual support provided to effectively reduce the levels of stress on the grandparent (Trivette et al., 1986; Vangelisti, 2009).

The second hypothesis pertained to the relationship between perceived social support and the well-being of the grandparent (Kresak et al., 2014; McCallion et al., 2004). It was hypothesised that perceived social support would have a positive relationship with the well-being of the grandparents. This hypothesis was also supported by the results of the current study and was in line with previous literature (Kresak et al., 2014; McCallion et al., 2004) as it was found that as perceived need for types of support increased, so did the well-being of the grandparent. This finding suggests that if the needs for different types of support for the grandparent are identified, it may potentially increase their well-being (both general well-being and child-related well-being as measured by the PWBI). The literature has indicated that with the increase in well-being, grandparents may have positive experiences when raising a grandchild with a disability, which can now, cautiously, be inferred to be the same for grandparents in this study context (McCallion et al., 2004).

The final hypothesis posited that there would be an inverse relationship between stress and the well-being of the grandparents because of the previously documented influences of stress on the well-being of grandparents raising a child with a disability in the literature (Brown et al., 2017; McCallion et al., 2004). The results of the current study supported this hypothesis; it was indicated that as the stress of the grandparent increased, their well-being was reduced. The

reduced levels of well-being due to stress is consistent with the literature (Brown et al., 2017; Kresak et al., 2014; Kresak & Gallagher, 2014; McCallion et al., 2004). It therefore provides evidence that in the current context, grandparents raising their grandchild with a disability may be at a heightened risk of having lower levels of well-being. As a result, it can be inferred that the lowered levels of well-being due to elevated levels of stress may affect the grandparent's ability to provide the necessary care to their grandchild in the current study (McConnell & Savage, 2015).

### **6.8. The Mediating and Moderating Effects of Perceived Social Support**

The current study further sought to investigate the mechanisms by which perceived social support influences the relationship between stress and well-being. As indicated in the parenting literature, perceived social support has been found to act, in certain cases, as a mediator (Sipal & Sayin, 2013; Skok et al., 2006). Other studies have attempted to identify the moderating effect of perceived social support, in combination with other constructs such as parenting stress and financial difficulties, child disability and ineffective parenting but not well-being (McConnell et al., 2011). The current study sought to verify the mediating and moderating effects of perceived social support on stress and well-being for this population of grandparents raising their grandchild.

In terms of the moderating effects of the perceived need for types of support between stress and well-being, the current study did not obtain any significant moderating effects of perceived social support. This result is in line with other studies conducted on parents raising a child with a disability (Quittner et al., 1990; Skok et al., 2006; Tak & McCubbin, 2002), which would mean that the perceived need for types of support in the current context of grandparents raising their grandchild with a congenital disability may not alter (buffer) the relationship between stress and well-being but accounts for the relationship between these variables which are often reported (Cohen & Wills, 1985). According to Quittner et al. (1990), it is possible that the lack of moderating or buffering effects of perceived social support may not be present in situations where there is chronic stress. Although the level of chronic stress was not measured in the current study, it is possible that the parenting grandparents in this study may be experiencing accumulated stress to the point of distress. This may be due to the accumulating effects of parenting and caregiving demands, the disability characteristics of their grandchild as well as the

socio-economic factors that they face daily (Doley et al., 2015), which may inhibit their ability to identify their support needs. As in the case of most of the grandparents in this study, it is also possible that these strains have accumulated since the birth of their grandchild, or even before this due to family strains and poverty challenges they have experienced over the years (Du Preez et al., 2015; Kirby & Sanders, 2012).

The challenge, however, lies in the potential harm that accumulated stress may have on parenting grandparents, such that, in the presence of heightened stress or distress, grandparents have been shown to experience poor problem-solving and needs appraisal (Pruchno & McKenney, 2002). Furthermore, the past research has shown that poor access to respite and helpful support, together with the accumulation of stress over a large period of time, can leave grandparents with low feelings of self-worth (Du Preez et al., 2015) and also poor satisfaction as a parent (Kresak et al., 2014). Therefore, reducing the levels of stress is critical for the grandparents raising their grandchild with a disability (Kresak & Gallagher, 2014).

On the other hand, a causal effect between the perceived need for types of support and the well-being of grandparents was found, where the relationship between stress and well-being is weakened in the presence of perceived need for types of support. This indicates a strong mediating effect of the perceived need for types of support on the constructs of stress and grandparent well-being, where the relationship between stress (PSS) and well-being (PWBI) seen in Table 5.13 occurs only because of the perceived need for types of support (SFS). That is, in the case of poor identification of need for types of support, there will be a greater influence on the grandparent's well-being rather than their stress. However, as previously shown, in periods of high stress, there is a possibility of poorer identification of needs for support (Figure 5.1). It is therefore crucial to assist grandparents in identifying their support needs in the presence of high degrees of stress. This is essential information for intervention practices in ECI, which should be geared towards providing parenting grandparents with the social support they require. This mediating effect of perceived need for types of support shows that merely facilitating the process of identifying support needs can intercede the effect of the stress on well-being before social support is even accessed. However, this mediating result also highlights the need for intervention services to be aware of the unique needs which grandparent caregivers may require (Demirtepe-Saygili & Bozo, 2011; Gallagher et al., 2010; Kresak et al., 2014). Therefore, intervention may



focus on decreasing the stress of grandparents, which would improve their ability to identify perceived need for types of support with an improved well-being. Alternatively, there needs to be better facilitation of identification of support needs if the stress of the grandparent cannot be decreased. Furthermore, by assessing these various needs for social support, it is possible to facilitate the organising of the resources (such as family, friends and social groups) around the grandparent so that the support will be effective in meeting their needs (Trivette, Dunst, & Hamby, 2010).

The findings of this study therefore support the suggestion that social support as both a family resource and material resource, as per the DSA (Guralnick, 2011), may, in fact, function as an important resource to grandparents raising their grandchild with a congenital disability. However, the current study also shows that it is important to delve deeper into the construct of social support to understand what aspect of this multi-dimensional construct can function as a resource. The causal effect of perceived need for types of support on the well-being of grandparents shows that the use of the term “social support” as a meta-construct (Haber et al., 2007) cannot be used loosely. This result further highlights that researchers need to be aware of and specific in distinguishing which dimension (qualitative or quantitative) (Thoits, 2011; Vangelisti, 2009) is being measured in the specific context of their study.

On the other hand, the positive influences of perceived need for types of support on the grandparent’s well-being indicated that identifying the needs for support of the grandparents may be a critical precursor to ensuring that the social support received is helpful to the grandparents, which in turn has an effect on their well-being (Trivette et al., 1986). There is a need for social support to be more helpful and more specific to the needs of the grandparent, especially if it stems from their assets, such as their informal networks (Kresak et al., 2014) and formal services (Trivette et al., 1986). Emotional support in the form of support groups specific to grandparents raising their grandchild with a congenital disability has been identified as a great need to the population in the current study and in other studies (McCallion et al., 2004).

This study further highlights that for social support to be effective, it has to be based on the assumption that grandparents are at a risk of social isolation due to the extensive amount of time and energy invested in parenting and caregiving demands of their grandchild with a disability.

Furthermore, grandparents have contextual factors, such as family conflicts, which may affect their ability to obtain parenting assistance from their child's other parent as well as financial burdens which contribute to their stress and well-being. The current study has shown that, in comparison to parents, grandparents raising their grandchild with a congenital disability have unique characteristics, such as their age, which is accompanied by age-related health issues as well as poorer physical abilities. The physical limitations of grandparents are more relevant to grandparents than younger parents, which may be further compromised by the health issues that accompany stress. In addition, compared to the parents, the increase in the severity of the grandchild's physical disability and behaviour as they get older (Gardiner et al., 2018) further becomes a concern for the grandparents because of their already present age-related health issues and physical limitations. Furthermore, unlike parents, grandparents do not fit in the conventional "parent-group". Grandparents require specific needs to be met and therefore a generic form of intervention, aimed at caregivers in general, may not be effective or helpful to them.

The results of this study further indicate that intervention should cater for the informational needs regarding their grandchild's disability such that they have positive parenting mechanisms which contribute to positive parenting skills amidst the grandchild's disability (McCallion et al., 2004). The need for respite services is another crucial indication for intervention to be implemented so that grandparents are able to take essential breaks from caregiving to decrease their stress levels while improving their well-being. Furthermore, grandparents require services to be sensitive to their emotional needs specific to their worries and concerns, such that the grandparents are able to express these on a safe platform, especially regarding their challenges related to raising their grandchild with a disability (Brown et al., 2017). Through specific support groups for such grandparents, there is a greater likelihood that they will be less isolated and more able to maintain meaningful social ties with other grandparents who they relate to due to their similar situations (McCallion et al., 2004). Services should facilitate the grandparent's advocacy for and access to the relevant sources of support and therapeutic services for their grandchild within their community. Furthermore, the family structure of parenting grandparents represents an integral part of the family structure, which has the important responsibility of providing the child with a safe and nurturing environment so that positive developmental outcomes for the child are achieved. Intervention should consider the conflicts within the family structure which can negatively influence the grandparent's well-being as a parent. The results of the current

study also highlight the need for governmental services to acknowledge the potential poverty in which most of these grandparents live while raising their grandchild with a disability. The financial costs of accommodating their grandchild's special needs should be considered in terms of the allocations of social grants to alleviate at least part of the financial difficulties for this population of grandparents.

As a result, it is crucial that any support provided to these grandparents needs to match the types of support which the grandparents perceived to be a priority. Following the above assumptions, this study has highlighted that there is a need for intervention that is less prescriptive and less generic for this specific population of grandparents (Gallagher et al., 2010). With intervention following these assumptions, there is a greater possibility that the support provided to the grandparent may be perceived as being useful and helpful, which may improve their levels of well-being (Gallagher et al., 2010; Kresak et al., 2014; Vangelisti, 2009). As a result, there is a greater chance of altering and improving the family patterns of interaction required for better cognitive and social developmental outcomes for the grandchild with a congenital disability (Guralnick, 2015).

## **6.9. Summary**

This chapter discussed and interpreted the results that were obtained in the current study. The relationships between the three constructs of stress, well-being and perceived social support were discussed in light of past research and in terms of their implications to the population of parenting grandparents who participated in the study. Further discussion was offered pertaining to the identified mediating effects of the perceived needs for types of support on the relationship between stress and well-being of the parenting grandparents. The implications for intervention with grandparent caregivers were also discussed.

## **Chapter 7: Conclusion**

### **7.1. Introduction**

This chapter concludes the current study. A summary of the most critical findings is provided together with the clinical implications of the study. An evaluation is also given in terms of the strengths and limitations of the study. Recommendations for future research are offered in the context of grandparents raising their grandchild with a congenital disability.

### **7.2. Summary of Study Findings**

The current study explored the relationship between perceived social support, stress (both parenting and caregiving) and well-being of grandparents raising their grandchild with a congenital disability in the Western Cape, South Africa. The study was conducted to address the gap in the literature regarding the relationship between perceived social support, stress and well-being for grandparents raising their grandchild with a congenital disability. The construct of perceived social support was initially to be measured by both the perceived needs for types of support (Trivette, Deal, & Dunst, 1986) and the helpfulness of the available support (Vangelisti, 2009). However, the poor reliability of the measure of helpfulness of support led to its exclusion from analysis, which left only the perceived need for types of support as a support variable of interest.

The current study tested the correlations between the three variables of stress (Parental Stress Scale – PSS), well-being (Personal Well-Being Index – PWBI) and the perceived needs for types of support (Support Functions Scale – SFS) to see if there were any relationships that existed between these three variables. A positive correlation between perceived need for types of support and the well-being of the grandparents indicated that as the perceived need for types of support increased, the well-being of the grandparents also increased. This meant that the well-being of grandparents may be increased if they are able to perceive what types of support they require (McCallion et al., 2004). On the other hand, a negative correlation was found between perceived need for types of support and the stress of grandparents, which indicated that with greater levels of the perceived need for types of support, the grandparent may experience lower levels of stress (Gallagher et al., 2010). Finally, a negative correlation was found between stress and well-being,

which suggested that if the amount of stress increased, the levels of well-being of the grandparents was reduced (Pandialagappan & Ibrahim, 2018).

Following these correlations, the three variables were analysed using Structural Equation Model to identify ways in which they related to each other in terms of their causal pathways (Figure 5.1). The results showed that a causal pathway existed between PSS, SFS and PWBI but not between PSS and PWBI (Table 5.14). This result explained the correlational relationship between PSS and PWBI, which was indirect in nature because of the presence of SFS, which acted as a full mediator between the two variables. Therefore, there are indications that there is no direct relationship that exists between PSS and PWBI. This relationship can be explained only through the presence of SFS because PSS has a direct effect on SFS.

### **7.3. Clinical Implications of Study**

This study demonstrated that the presence of perceived need for types of support has a positive effect on the physical and emotional well-being of grandparents raising their grandchild with a congenital disability. Stress has a negative effect on the well-being of the parenting grandparents. However, this relationship is accounted for indirectly through perceived needs for type of support. This study highlights several clinical implications that need to be considered when working with the population of grandparents raising their grandchild with a congenital disability in contrast to conventional caregivers, such as parents of children with a congenital disability. Firstly, compared to biological parents, grandparents raising their grandchild are older in age, and face age-related physical limitations which may contribute to their difficulty in keeping up with the grandchild's energy levels and challenging disability-related behaviours. For example, grandparents may struggle to physically move their grandchild during daily caregiving routine activities (Samuel et al., 2017). It is therefore important to provide support for these physical caregiving strains of grandparents if they perceive it to be an important support need, especially as the grandchild also ages and physically grows (Gardiner et al., 2018; Gordon, 2018; Kim & Chung, 2016).

With the increase in numbers of parenting grandparents indicated by the literature and South African statistics (Dolbin-Macnab et al., 2016; Dolbin-MacNab & Yancura, 2017; Lehohla, 2011), it is crucial that the well-being of grandparent caregivers of a child with a disability is

addressed so that they are able to fulfil their expected parenting role for their grandchild. The low scores on well-being in the current study indicate that grandparent caregivers of children with a disability are a special population at risk when compared to parents. The lower levels of physical general well-being of the majority of the grandparents in the current study were associated with the feeling of being unwell. Literature has cautioned that grandparents tend to ignore their own medical and health problems to continue with their parenting responsibilities (Brown et al., 2017). However, parenting grandparents may strive to maintain a strong and able image out of fear of losing the care and guardianship of their grandchild (Noy & Findler, 2016). It is therefore important that interventionists are aware that grandparents may not always disclose their poor physical well-being, especially when asked about their lack of coping abilities in order to not be perceived as being ineffective in raising their grandchild (McCallion et al., 2004; Noy & Findler, 2016). It is also important to acknowledge the emotional conflict which grandparents may face between their obligations towards their grandchild and family (Dolbin-Macnab et al., 2016), and what they are able to physically and emotionally provide for their grandchild as a result of their age-related limitations.

This study has also highlighted that to address the high levels of stress and poor well-being of the parenting grandparent caregivers of a child with a disability successfully, it is crucial that the support provided matches their perceived needs (Trivette et al., 1986; Vangelisti, 2009). While this implication also applies to parents of children with a disability, the mediating effect of the perceived need for types of support on the relationship of stress and well-being indicates that identifying the specific and distinct perceived needs of grandparents may be an important factor to address well-being directly. Intervention should consider grandparent-specific challenges, such as potential family conflict, role conflict in parenting grandparents due to the generational gap, as well as age-related physical limitations which contribute to their stress while trying to understand and manage their grandchild's disability.

The grandparents in the current study indicated that emotional support represents a high support need in terms of being able to speak to someone when things worry them and to have encouragement when their life is challenging. This is an important indicator of possible social isolation of this grandparent cohort, which appears to be a common experience of grandparents who raise their grandchild with a disability (Gallagher et al., 2010; Kresak & Gallagher, 2014;

McCallion et al., 2004). Intervention should also be sensitive that grandparents raising their grandchild with a congenital disability can experience social rejection among their non-parenting grandparent peers or grandparents who are raising their grandchild without a disability.

Furthermore, it is crucial to support grandparents with the necessary strategies to manage their grandchild's disability-related behaviour so that their family and friends are more willing to provide respite when needed. The findings of this study show that raising a grandchild with a congenital disability is stressful for the grandparents because of the increased allocation of time and energy to this responsibility. The increase in time and energy may be linked to disability-related issues, such as poor mobility, learning difficulties, sensory integration disorders, impulsivity, communication difficulties, fussy eating, as well as the time spent in therapies, all of which have been identified as areas of stress for parenting grandparents (Gallagher et al., 2010; Hillman & Anderson, 2019). The disability-related behaviours of the grandchild, identified as another source of stress in this study, have also highlighted that it is crucial for intervention to support the informational needs of the parenting grandparent (Guralnick, 2005). The provision of information specific to their grandchild's disability may contribute to their confidence and self-efficacy in raising their grandchild (Gallagher et al., 2010). It is also implied that specific information in terms of practical ways of managing their grandchild's disability-related behaviour, such as aggression, melt-downs or tantrums, may be crucial (Gordon, 2018).

The use of support groups as a platform specific to grandparents raising their grandchild with a congenital disability may be a useful method of addressing these disability-related challenges, social isolation and sources of stress (Brown et al., 2017). These support groups may also be an important source of emotional support for the grandparents, which was identified as an important type of support need for the grandparents in the current study (Brown et al., 2017). However, interventionists should also be mindful that these intervention programmes and support groups need to be designed specifically for grandparents raising their grandchild with a congenital disability so that they can identify with others in similar positions and thus have a sense of belonging to these support groups (McCallion et al., 2004).

There is a need for greater community awareness and acknowledgement of grandparents who are raising their grandchild within these communities so that informal support, which is more

sustainable (McWilliam & Scott, 2001) can be offered to grandparents (Kresak & Gallagher, 2014). Communities thus need to be informed and educated about the various disabilities so that they can support the grandparents by understanding the grandchild's disability. This could also lead to greater inclusion of the grandchild within the community (Kresak, Gallagher, & Kelley, 2014), allowing for more opportunities to participate in family-orchestrated child experiences (Guralnick, 2005). Informal support provided by the communities may therefore be an important form of support for the grandparents, especially when seeking respite (Hillman & Anderson, 2019; McCallion et al., 2004), but also to reduce their social isolation within the community (Kresak et al., 2014).

Moreover, because social support represents an important resource to families raising a child with a disability (Guralnick, 2011), it is crucial for intervention services to help grandparents identify the various sources of social supports available within their community which match their needs (Patel et al., 2018). By empowering grandparents to mobilise the supports from their community, it is possible to reduce the effect of these various challenges before they become sources of stress or have a detrimental effect on their well-being. Without addressing the sources of stress, raising a grandchild with a disability may become a burden and strain, rather than a source of enjoyment and satisfaction for the grandparents (Buchanan & Rotkirch, 2018).

## **7.4. Evaluation of the Study**

The following sections present the strengths and limitations of the study.

### ***7.4.1. Strengths of study.***

The strength of this study was that it included the perceptions of co-parenting and sole-parenting grandparents raising a grandchild with a congenital disability who are an under-researched population. It also took into account and adapted for the potential low levels of literacy in this population and sought to include grandparent caregivers from across the prevalent language groups in the research context (Brock-Utne, 2015; Research Center Survey, 2016).

As a result, the study was able to use a survey design in spite of the low levels of literacy prevalent in the grandparent population (Lehohla, 2011). Furthermore, the interviews were carried out in the mother tongue of the participants, namely IsiXhosa, Afrikaans or English,



which ensured that they were at ease in sharing information during the interview (Elmir et al., 2011).

The strength of the study is also reflected in the rigor with which the translations of the measures were done. The translations were conducted according to Brislin's (1986) translation process. This translation process provided a clear process of ensuring that the items of the measures preserved their linguistic equivalence while being culturally appropriate to the IsiXhosa and Afrikaans contexts of the study (Brislin, 1986).

The study's strength further lies in the adaptation of the administration of the measures where the use of graphic symbols provided a form of visual support together with the text for the participants (Stewart et al., 2012). A structured interview format was used rather than a self-completing questionnaire process, which accommodated for the low levels of literacy of the grandparents (Stewart et al., 2012). The involvement of the researcher in the completing of the survey with each participant as soon as the participant had voiced or pointed to their response reduced any chance of missing data and ensured that each measure was completed accordingly (Kelley et al., 2003).

The use of a procedural script for all the interviews ensured that each interview was conducted the same way by the two research assistants. This contributed to the strength of the study by ensuring the procedural reliability of each interview.

Each interview was carried out in the home or at a location with which the grandparents were already familiar. The familiar environment facilitated the grandparent's comfort and ease of sharing information, which contributed to the building of a rapport with the grandparent (Elmir et al., 2011). This may therefore have resulted in the grandparents' being more at ease, ensuring more reliable information with reduced Hawthorn effect.

The study also provides for the content validity of three measures used in this study, namely the Parental Stress Scale (Berry & Jones, 1995), the Personal Well-Being Index (Trivette & Dunst, 1986) and the Support Functions Scale (Dunst & Trivette, 1986) to this specific South African population.

The current study provided a deeper perspective of the construct of social support, where perceived social support was analysed in relation to the constructs of stress and well-being (Haber et al., 2007). The novelty of this study lies in the exploration of the relationships of these three constructs specific to the context of grandparents raising their grandchild with a congenital disability.

A final strength of this study lies in the fact that an analysis of the relationships between stress, perceived need for types of support and well-being of grandparents raising their grandchild was carried out. However, further to this, an analysis of the causal pathway of the three variables was also undertaken to identify the ways in which the three variables related to each other. This provided further information and understanding of how perceived social support acts as a full mediator between stress and well-being.

#### ***7.4.2. Limitations of study.***

The sample of 50 parenting grandparents (co-parenting and sole parenting) who took part in this study was small in contrast to the actual number of grandparents who raise their grandchild with a disability within the Western Cape and South Africa at large. Therefore, the results of this study cannot be generalised to other areas in the Western Cape, to other provinces within South Africa or to a broader context.

A further limitation of the current study was the poor reliability of the FSS (Dunst et al., 1984) after its adaptation to the context of the parenting grandparents of this study. As a result, the helpfulness of the available sources of support of the grandparents could not be measured and analysed in relation to the stress and well-being of the grandparents. The poor reliability of the FSS showed that although this measure was reported to have adequate reliability by its authors (Dunst et al., 1984), and has been extensively used in various peer-reviewed studies world-wide, the measure was not valid for the context of the current study. This highlights the challenge of the use of measurement instruments devised in different countries and contexts and applying them in a different culture or country. This has specifically been emphasised by Marfo and Pence (2009) as a limitation when conducting cross-cultural research. Furthermore, as clarified by Boynton and Greenhalgh (2004), the change in the reliability of a measure may often be due to the differences in the participants of the study from the participants on which the measure was

initially devised. In addition, the environmental context which differs from the original devised population may have had an additional influence on the reliability of the measure rather than the poor understandability of the items of the measure (Boynton & Greenhalgh, 2004).

### **7.5. Recommendations for Further Research**

It is recommended that future studies consider using larger samples of parenting grandparents with a focus on other areas of the Western Cape or other provinces within South Africa. It will also be important to identify whether the relationships between perceived social support, stress and well-being of the parenting grandparents vary in other communities in South Africa. Some communities may be more helpful towards grandparents raising their grandchild with a disability, depending on their cultural perceptions of the grandchild's disability (Penn et al., 2010). Furthermore, this information will provide a clearer perspective of what forms of informal support grandparents in other communities have access to and whether these are particularly helpful supports. Additionally, the perceived need for types of support may also vary in terms of whether grandparents need access to more emotional, informational, instrumental and financial support compared to the grandparents of the current study.

It will also be beneficial to identify whether grandparent peer-networks are present in communities and whether these act as a positive support for grandparents raising a grandchild with a disability in other communities across South Africa. This may inform research in ways that grandparents provide the necessary support towards each other, which may also better inform intervention regarding how supportive peer-networks of grandparents influence the stress and well-being of grandparents raising their child with a congenital disability.

Measures devised on different or other international populations and contexts need to be validated for the South African population before they are used clinically. The poor reliability of the adapted Family Support Scale (FSS) showed that adaptations through translation were not enough to meet the reliability criteria. Therefore, there is a greater need for initiatives to create South African based measures for use on South African parenting grandparents (Marfo & Pence, 2009).

Addressing this limitation will help to address a paucity of South African research on grandparents raising their grandchild with a disability. The use of a qualitative and quantitative mixed method may be a reliable technique of developing these South African measures. Themes which are identified as part of in-depth qualitative interviews with grandparents may provide the dimensions to be measured to increase the reliability and validity of these instruments. For example, in the case of the construct of social support specific to perceived social support, there is a need for more questionnaires that focus on measuring the perceived helpfulness of available social support, specifically for grandparents raising their grandchild with a congenital disability.

## **7.6. Summary**

This chapter summarised the significant findings of this study. The clinical implications, strengths and limitations and recommendations for future research were also provided.

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## **Appendices**

## Appendix A: Original Parental Stress Scale

*Berry and Jones (1995)*

The following statements describe feelings and perceptions about the experience of being a parent. Think of each of the items in terms of how your relationship with your child or children typically is. Please indicate the degree to which you agree or disagree with the following items by placing the appropriate number in the space provided.

1 = Strongly disagree 2 = Disagree 3 = Undecided 4 = Agree 5 = Strongly agree

1	I am happy in my role as a parent	
2	There is little or nothing I wouldn't do for my child(ren) if it was necessary.	
3	Caring for my child(ren) sometimes takes more time and energy than I have to give.	
4	I sometimes worry whether I am doing enough for my child(ren).	
5	I feel close to my child(ren).	
6	I enjoy spending time with my child(ren).	
7	My child(ren) is an important source of affection for me.	
8	Having child(ren) gives me a more certain and optimistic view for the future.	
9	The major source of stress in my life is my child(ren).	
10	Having child(ren) leaves little time and flexibility in my life.	
11	Having child(ren) has been a financial burden.	
12	It is difficult to balance different responsibilities because of my child(ren).	
13	The behaviour of my child(ren) is often embarrassing or stressful to me.	
14	If I had it to do over again, I might decide not to have child(ren).	
15	I feel overwhelmed by the responsibility of being a parent.	
16	Having child(ren) has meant having too few choices and too little control over my life.	
17	I am satisfied as a parent	
18	I find my child(ren) enjoyable	



## Appendix B: Original Personal Well-Being Index

*Carol M. Trivette and Carl J. Dunst*

Name \_\_\_\_\_ Date \_\_\_\_\_

This scale includes a list of some of the ways people feel at different times. No one person experiences all of these things. Please circle the response that best indicates how often you felt or experienced each item during the past 2 weeks. Please answer all of the questions.

How often did you experience the following during the past 2 weeks:	Never	Once in a While	Some-times	Often	Quite Often
1. Feeling trapped by my responsibilities as a parent	1	2	3	4	5
2. Feeling that my life is going just great	1	2	3	4	5
3. Finding it easy to physically take care of my child	1	2	3	4	5
4. Feeling under-the-weather or ill	1	2	3	4	5
5. Feeling uneasy or scared without knowing why	1	2	3	4	5
6. Feeling tired or fatigued after caring for my child	1	2	3	4	5
7. Feeling glad about my child's future	1	2	3	4	5
8. Feeling tired or run-down	1	2	3	4	5
9. Seeing no end to the demands my child makes on me	1	2	3	4	5
10. Having lots of energy to get things done	1	2	3	4	5
11. Feeling blue or depressed	1	2	3	4	5
12. Having lots of energy to keep up with my child	1	2	3	4	5
13. Finding pleasure in the things my child does	1	2	3	4	5
14. Feeling on top of the world	1	2	3	4	5
15. Finding caring for my child puts a strain on me	1	2	3	4	5
16. Feeling in tip-top shape	1	2	3	4	5

*Winterberry Assessment Scales & Instruments*

## Appendix C: Original Support Functions Scale

### (Short Version)

*Carl J. Dunst and Carol M. Trivette*

Name \_\_\_\_\_ Date \_\_\_\_\_

This scale includes 20 different types of assistance that people sometimes find helpful. This questionnaire asks you to indicate how much you need help in each of these areas. Please circle the response that best describes your needs. Please answer all the questions.

To what extent do you feel a need for any of the following types of help or assistance?		Never	Once in a While	Some-times	Often	Quite Often
1.	Someone to talk to about things that worry you	1	2	3	4	5
2.	Someone to provide money for food, clothes, and other things	1	2	3	4	5
3.	Someone to care for your child on a regular basis	1	2	3	4	5
4.	Someone to talk to about problems with raising your child	1	2	3	4	5
5.	Someone to help you get services for your child	1	2	3	4	5
6.	Someone to encourage you when you are down	1	2	3	4	5
7.	Someone to fix things around the house	1	2	3	4	5
8.	Someone to talk to who has had similar experiences	1	2	3	4	5
9.	Someone to do things with your child	1	2	3	4	5
10.	Someone on whom you can depend	1	2	3	4	5
11.	Someone to hassle with agencies or businesses when you can't	1	2	3	4	5
12.	Someone to lend you money	1	2	3	4	5
13.	Someone who accepts your child regardless of how he or she acts	1	2	3	4	5
14.	Someone to relax or joke with	1	2	3	4	5
15.	Someone to help with household chores	1	2	3	4	5
16.	Someone who keeps you going when things seem hard	1	2	3	4	5
17.	Someone to care for your child in emergencies or when you must go out	1	2	3	4	5
18.	Someone to talk to when you need advice	1	2	3	4	5
19.	Someone to provide you or your child(ren) transportation	1	2	3	4	5
20.	Someone who tells you about services for your child or family	1	2	3	4	5

*Winterberry Assessment Scales & Instruments*

## Appendix D: Original Family Support Scale

*Carl J. Dunst, Carol M. Trivette, and Vicki Jenkins*

Name \_\_\_\_\_

Date \_\_\_\_\_

Listed below are people and groups that oftentimes are helpful to members of a family raising a young child. This questionnaire asks you to indicate how helpful each source is to your family. Please circle the response that best describes how helpful the people and groups have been to your family during the past 3 to 6 months. If a source of help has not been available to your family during this period of time, circle the NA (Not Available) response.

How helpful has each of the following been to you in terms of raising your child(ren)?		Not Available	Not at All Helpful	Sometimes Helpful	Generally Helpful	Very Helpful	Extremely Helpful
1.	My parents	NA	1	2	3	4	5
2.	My spouse or partner's parents	NA	1	2	3	4	5
3.	My relatives/kin	NA	1	2	3	4	5
4.	My spouse or partner's relatives/kin	NA	1	2	3	4	5
5.	My spouse or partner	NA	1	2	3	4	5
6.	My friends	NA	1	2	3	4	5
7.	My spouse or partner's friends	NA	1	2	3	4	5
8.	My older child(ren)	NA	1	2	3	4	5
9.	Neighbors	NA	1	2	3	4	5
10.	Other parents	NA	1	2	3	4	5
11.	Co-workers	NA	1	2	3	4	5
12.	Parent group members	NA	1	2	3	4	5
13.	Social groups/clubs	NA	1	2	3	4	5
14.	Church members/minister	NA	1	2	3	4	5
15.	My family or child's physician	NA	1	2	3	4	5
16.	Early childhood intervention program	NA	1	2	3	4	5
17.	School/daycare center	NA	1	2	3	4	5
18.	Professional helpers (social workers, therapists, teachers, etc.)	NA	1	2	3	4	5
19.	Professional agencies (public health, social services, mental health, etc.)	NA	1	2	3	4	5
20.	_____	NA	1	2	3	4	5
21.	_____	NA	1	2	3	4	5

*Winterberry Assessment Scales & Instruments*

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**Appendix F: Modifications to Measures PSS, PWBI, SFS & FSS**





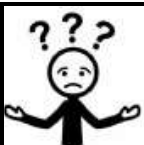


**Parental Stress Scale (PSS)**


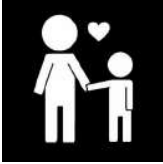

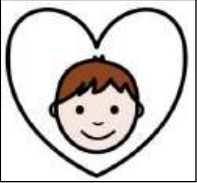



<b>Original instruction of PSS</b>
“The following statements describe feelings and perceptions about the experience of being a parent. Think of each of the items in terms of how your relationship with your child or children typically is. Please indicate the degree to which you agree or disagree with the following items by placing the appropriate number in the space provided.”
<b>Adapted instruction for grandparent caregivers</b>
“We will now look at how you feel about being a caregiver and measure how much stress you experience as caregiver. For each of these sentences think about how your relationship is with your grandchild who has a disability. So that we can measure how you experience the stress of raising your grandchild, we look at how much agree or disagree with the sentences we will read to you. This picture means you strongly agree, this one means you agree, this one means you disagree and this one means you strongly disagree”.

<b>Original Likert scale of the Parental Stress Scale</b>	<b>Content modification to responses on Likert scale</b>	<b>Format or presentation modification to Likert scale</b> Participant were required to point to their response instead of circling their response and visuals were added to the text labels	<b>Context modification</b>
Strongly disagree	Stays the same as original	 Strongly disagree	Instructions of measure modified from self-completion instructions to verbal instructions with pointing to response on Likert scale
Disagree	Stays the same as original	 Disagree	
Undecided	Stays same as original	 Undecided	
Agree	Stays the same as original	 Agree	
Strongly agree	Stays the same as original	 Strongly agree	



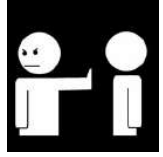





**Items of the PSS**

Original items of the PSS	<b>Content modification</b> <ul style="list-style-type: none"> <li>Content modification required for double-barrelled items</li> </ul>	<b>Context modification of items of PSS</b> <ul style="list-style-type: none"> <li>Wording of items modified</li> <li>Referents changed</li> </ul>	<b>Format and presentation modification of items of PSS</b> <ul style="list-style-type: none"> <li>Graphic symbols added to represent the core concept of each item</li> </ul>
1. I am happy in my role as a parent	No content modification required	1. You are happy in your role as a caregiver of your grandchild with a disability	
2. There is little or nothing I wouldn't do for my child(ren) if it was necessary		2. You would do everything you can for your grandchild with a disability	
3. Caring for my child(ren) sometimes takes more time and energy than I have to give		3. Caring for your grandchild with a disability sometimes takes more time and energy than you have to give.	
4. Having child(ren) has meant having too few choices and too little control over my life	Content modification required due to double-barrelled item	4. Raising your grandchild with a disability has meant having too little control over your own life.	
	Content modification required to double-barrelled item	18. Raising your grandchild with a disability has meant having too few choices	
5. I sometimes worry whether I am doing enough for my child(ren)	No content modification required	5. You sometimes worry whether you are doing enough for your grandchild with a disability	
6. The behaviour of my child(ren) is often embarrassing or stressful to me	Content modification required to double-barrelled item	6. The behaviour of your grandchild with a disability is often stressful to you	

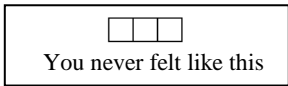
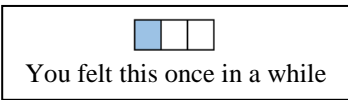
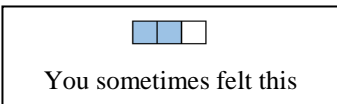
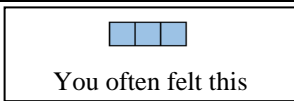
	Content modification required to double-barrelled item	15. The behaviour of your grandchild with a disability is often embarrassing to you	
7. I feel close to my child(ren)	No content modification required	7. You feel close to your grandchild with a disability	
8. I enjoy spending time with my child(ren)		8. You enjoy spending time with your grandchild with a disability	
9. My child(ren) is an important source of affection for me		9. Your grandchild with a disability is an important source of love for you	
10. Having child(ren) gives me a more certain and optimistic view for the future		10. Raising your grandchild with a disability gives you a more certain and positive view for the future	
11. The major source of stress in my life is my child(ren)		11. The major source of stress in your life is your grandchild with a disability	
12. Having child(ren) leaves little time and flexibility in my life		12. Raising your grandchild with a disability leaves little time and flexibility in your life	









<p>13. Having child(ren) has been a financial burden</p>		<p>13. Raising your grandchild with a disability is a financial burden</p>	
<p>14. It is difficult to balance different responsibilities because of my child(ren)</p>		<p>14. It is difficult to balance different responsibilities because of your grandchild with a disability</p>	
<p>15. If I had it to do over again, I might decide not to have child(ren)</p>		<p>16. If you had it to do over again, you might decide not to raise your grandchild with a disability</p>	
<p>16. I feel overwhelmed by the responsibility of being a parent</p>		<p>17. You feel overwhelmed by the responsibility of being a caregiver to your grandchild with a disability</p>	
<p>17. I am satisfied as a parent</p>		<p>19. You are satisfied as a grandparent</p>	
<p>18. I find my child(ren) enjoyable</p>		<p>20. You find your grandchild with a disability enjoyable</p>	



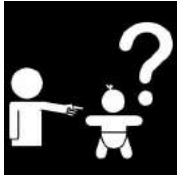




**Personal Well-Being Index (PWBI)**




<b>Original instruction</b>
“This scale includes a list of some of the ways people feel at different times. No one person experiences all of these things. Please circle the response that best indicates how often you felt or experienced each item during the past 2 weeks. Please answer all of the questions”
<b>Adapted instruction for grandparent caregivers</b>
“Now we are going to look at your well-being, and we will try to measure how often it happens, like how often do you feel tired or how often do you feel happy. This ranges from ‘I feel like this very often’ to ‘I feel like this never’”. This picture means you feel like this never, this one means you feel it once in a while, this picture means that you feel it sometimes and this one means you feel it often. We want to measure how much you have felt like this since the beginning of the month/last two weeks”

<b>Original Likert scale of PWBI</b>	<b>Content modification to responses on Likert scale</b>	<b>Format or presentation modification to Likert scale</b> Participant were required to point to their response instead of circling their response and visuals were added to the text labels	<b>Context modification</b>
Never	Stays the same as original		Instructions of measure modified from self-completion instructions to verbal instructions with pointing to response on Likert scale
Once in a while	Stays the same as original		
Sometimes	Stays the same as original		
Often	Stays the same as original		
Quite often	Option deleted due to complexity in understanding slight semantic variation (Sousa & Rojjanasrirat, 2010)		

**Items of the Personal Well-Being Index**





Original version of Personal Well-Being Index	Content modification <ul style="list-style-type: none"> <li>No content modification required</li> </ul>	Context modification of items of PWBI <ul style="list-style-type: none"> <li>Recall period modified</li> <li>Wording of items modified</li> <li>Referent changed</li> </ul>	Format and presentation modification of items of PWBI <ul style="list-style-type: none"> <li>Graphic symbols added to represent the core concept of each item</li> </ul>
1. Feeling that my life is going just great	No content modification required	1. Since the beginning of the month how often have you felt that your life is going just great	
2. Feeling trapped by my responsibilities as a parent		2. Since the beginning of the month how often have you felt trapped by your responsibilities as a caregiver of your grandchild with a disability	
3. Finding it easy to physically take care of my child		3. Since the beginning of the month how often have you found it easy to physically take care of your grandchild with a disability	
4. Feeling under-the-weather or ill		4. Since the beginning of the month how often have you felt unwell or ill	
5. Feeling uneasy or scared without knowing why		5. Since the beginning of the month how often have you felt uneasy or scared without knowing why	
6. Feeling tired or fatigued after caring for my child		6. Since the beginning of the month how often have you felt tired or exhausted after caring for your grandchild with a disability	

<p>7. Feeling glad about my child's future</p>		<p>7. Since the beginning of the month how often have you felt glad about your grandchild with a disability's future</p>	
<p>8. Feeling tired or run-down</p>		<p>8. Since the beginning of the month how often have you felt tired or run-down</p>	
<p>9. Seeing no end to the demands my child makes on me</p>		<p>9. Since the beginning of the month how often have you seen no end to the demands your grandchild with a disability makes on you</p>	
<p>10. Having lots of energy to get things done</p>		<p>10. Since the beginning of the month how often have you had lots of energy to get things done (e.g. household chores)</p>	
<p>11. Feeling blue or depressed</p>		<p>11. Since the beginning of the month how often have you felt down or depressed</p>	
<p>12. Having lots of energy to keep up with my child</p>		<p>12. Since the beginning of the month how often have you had lots of energy to keep up with your grandchild with a disability</p>	
<p>13. Finding pleasure in the things my child does</p>		<p>13. Since the beginning of the month how often have you found pleasure in the things your grandchild with a disability does</p>	






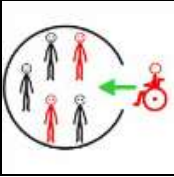
<p>14. Feeling on top of the world</p>		<p>14. Since the beginning of the month how often have you felt really happy</p>	
<p>15. Finding caring for my child puts a strain on me</p>		<p>15. Since the beginning of the month how often have you found that caring for your grandchild with a disability puts a strain on you</p>	
<p>16. Feeling in tip-top shape</p>		<p>16. Since the beginning of the month how often have you been feeling like you are in great shape</p>	







### Support Functions Scale (SFS)

<b>Original instruction</b>
This scale includes 20 different types of assistance that people sometimes find helpful. This questionnaire asks you to indicate how much you need help in each of these areas. Please <i>circle</i> the response that best describes your needs. Please answer all the questions. To what extent do you feel a need for any of the following types of help or assistance?
<b>Adapted instruction for grandparent caregivers</b>
“Now we will look at the types of support which you need and find helpful. To measure what supports you need and find helpful, we will look at how much you need this kind of help, and it varies from ‘never’ to ‘often’. This picture is for when you never need this help, this one is for when you need this help once in a while, this picture is for when you sometimes need this help and this one is for when you quite often need this help.”

Original Likert scale of the SFS	Content modification to responses on Likert scale	Format or presentation modification to Likert scale Participant were required to point to their response instead of circling their response and visuals were added to the text labels	Context modification
Never	Stays the same as original	 You never need this help	Instructions of measure modified from self-completion instructions to verbal instructions with pointing to response on Likert scale
Once in a while	Stays the same as original	 You need this help once in a while	
Sometimes	Stays the same as original	 You sometimes need this help	
Often	Stays the same as original	 You need this help often	
Quite often	DELETE this option due to complexity in understanding slight semantic variation (Sousa & Rojjanasrirat, 2010)		

**Items of the SFS**

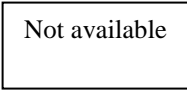
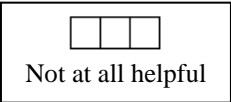
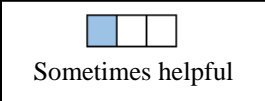
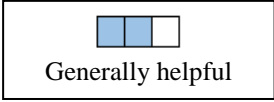
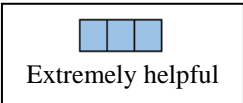
<p><b>Original version of SFS</b></p>	<p><b>Content modification of items of SFS</b></p> <ul style="list-style-type: none"> <li><i>No content modification required</i></li> </ul>	<p><b>Context modification of items of SFS</b></p> <ul style="list-style-type: none"> <li><i>Wording of items modified</i></li> <li><i>Referent changed</i></li> </ul>	<p><b>Format and presentation modification</b></p> <ul style="list-style-type: none"> <li><i>Graphic symbols added to represent the core concept of each item</i></li> </ul>
<p>1. Someone to talk to about things that worry you</p>	<p>No content modification required</p>	<p>1. How often do you feel you need someone to talk to about things that worry you</p>	
<p>2. Someone to help take care of your child</p>		<p>2. How often do you feel you need someone to help take care of your grandchild with a disability</p>	
<p>3. Someone to talk to when you have questions about raising your child</p>		<p>3. How often do you feel you need someone to talk to when you have questions about raising your grandchild with a disability</p>	
<p>4. Someone who loans you money when you need it</p>		<p>4. How often do you feel you need someone who can lend you money when you need it</p>	
<p>5. Someone to encourage or keep you going when things seem hard</p>		<p>5. How often do you feel you need someone to encourage or keep you going when things seem hard</p>	
<p>6. Someone who accepts your child regardless of how he or she acts</p>		<p>6. How often do you feel you need someone who accepts your grandchild with a disability regardless of how he or she acts</p>	

<p>7. Someone to help with household chores</p>		<p>7. How often do you feel you need someone to help you with household chores</p>	
<p>8. Someone to relax or joke with</p>		<p>8. How often do you feel you need someone to help you with household chores</p>	
<p>9. Someone to do things with your child</p>		<p>9. How often do you feel you need someone to help your grandchild with a disability</p>	
<p>10. Someone to provide you or your child transportation</p>		<p>10. How often do you feel you need someone to help your grandchild with a disability or you with transportation</p>	
<p>11. Someone to hassle with agencies or individuals when you can't</p>		<p>11. How often do you feel you need someone to follow up with SASSA (e.g. grants) or hospital services (e.g. therapy/doctor appointments) when you can't</p>	
<p>12. Someone who tells you about services for your child or family</p>		<p>12. How often do you feel you need someone who can tell you about services for your grandchild with a disability or your family</p>	










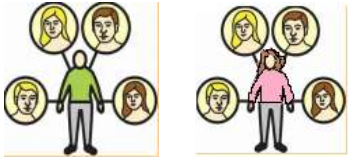
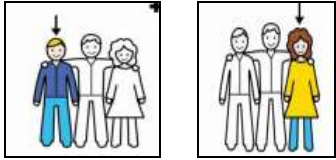

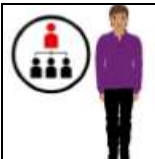


**Family Support Scale (FSS)**


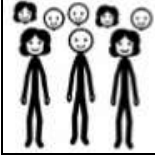

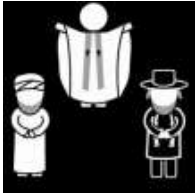

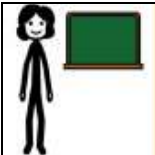


<b>Original instruction</b>
Listed below are people and groups that oftentimes are helpful to members of a family raising a young child. This questionnaire asks you to indicate how helpful each source is to <i>your family</i> . Please <i>circle</i> the response that <i>best describes</i> how <i>helpful</i> the people and groups have been to your family during the past 3 to 6 months. If a source of help has not been available to your family during this period of time, circle the NA (Not Available) response. How <i>helpful</i> has each of the following been to you in terms of raising your child(ren)?
<b>Adapted instruction for grandparent caregivers</b>
“Now we will look at how the people and groups who are help to you when raising your grandchild who has a disability. So that we can measure how helpful these different people and groups are to you, the pictures vary from not available to very helpful. So this picture means that the person or group is not there in your life, this picture means that the person or group is not helpful, this one means that they are sometimes helpful and this one means that they are very helpful to you. We want to look at how helpful these people or groups have been to you since the past six months (show visual timescale on calender).”

<b>Original Likert scale of the FSS</b>	<b>Content modification to responses on Likert scale</b>	<b>Format or presentation modification to Likert scale</b> Participant were required to point to their response instead of circling their response and visuals were added to the text labels	<b>Context modification</b>
Support not available	Stays the same as original		Instructions of measure modified from self-completion instructions to verbal instructions with pointing to response on Likert scale
Not at all helpful	Stays the same as original		
Sometimes helpful	Stays the same as original		
Generally helpful	Stays as original		
Very helpful	DELETE this option due to complexity in understanding slight semantic variation (Sousa & Rojjanasrirat, 2010)		
Extremely helpful	Stays as original		

**Items of the FSS**







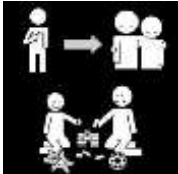
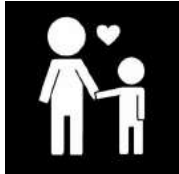
Original version	Content modification <ul style="list-style-type: none"> <li>• addition of new dimensions</li> <li>• items dropped</li> </ul>	Context modification <ul style="list-style-type: none"> <li>• Referent modified</li> <li>• Wording of items modified</li> <li>• recall period changed from '3 to 6 months' to 'past 6 months'</li> </ul>	Format and presentation modification <ul style="list-style-type: none"> <li>• Graphic symbols added to represent the core concept of each item</li> <li>• Visual reference of a calender used to represent 'past 6 months'</li> </ul>
5. My spouse or partner	No content modification required	1. How helpful has your husband/wife or partner been	
8. My older child(ren)		2. How helpful have your older child(ren) been	
9. Neighbors		3. How helpful have your neighbours been	
1. My parents		4. How helpful have your parents been	
		Item added due to literature highlighting that grandparents in South Africa are often raising more than one child in their household (Casale, Wild, Cluver, & Kuo, 2014)	5. How helpful have your other grandchildren been
3. My relatives/kin	No content modification required	6. How helpful have your relatives been	
6. My friends		7. How helpful have your friends been	


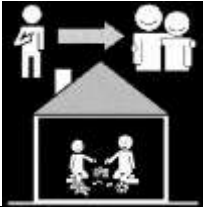


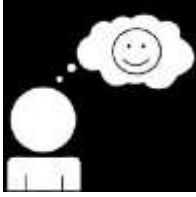


<p>2. My spouse or partner's parents</p>		<p>8. How helpful have the parents of your husband/wife or partner been</p>	
<p>4. My spouse or partner's relatives/kin</p>		<p>9. How helpful have the relatives of your husband/(wife) or partner been</p>	
<p>7. My spouse or partner's friends</p>		<p>10. How helpful have the friends of your husband or partner been</p>	
	<p>Item added as some grandparents may have a nanny to care for the child when they have to work (Simson, 2013)</p>	<p>11. How helpful the nanny of your grandchild with a disability been</p>	
	<p>Item added as for those grandparents who are still working and who rely on their employer for a salary (Statistics South Africa, 2014a)</p>	<p>12. How helpful has your employer</p>	
	<p>Item added as grandparents often form close connections with other grandparents who are in a similar situation as caregivers (Kirby &amp; Sanders, 2012)</p>	<p>13. How helpful have other grandparents raising their grandchild with a disability</p>	
<p>10. Other parents</p>	<p>No content modification required</p>	<p>14. How helpful have other grandparents been</p>	

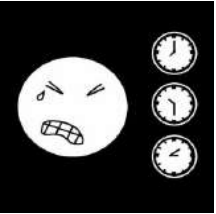




12. Parent group members		15. How helpful have members of grandparent caregivers support group been	
11. Co-workers		16. How helpful have your co-workers been	
13. Social groups/clubs		17. How helpful have members of your social groups/clubs been	
14. Church members/minister		18. How helpful have your fellow religious group members or spiritual leaders been	
15. My family or child's physician		19. How helpful has your family doctor or the doctor of your grandchild with a disability been	
16. ECI program	Item merged with item 23	-----	-----
17. School/day-care centre	No content modification required	21. How helpful has your grandchild with a disability's care centres/crèche been	
18. Professional helpers (social workers, therapists, teachers, etc.)		22. How helpful have professional helpers (e.g. social worker, community rehab worker, therapists, nurses) been	
19. Professional agencies (public health, social services, mental health, etc.)		23. How helpful have professional services at your local clinic (social services, mental health etc.) been	
20. Other _____		24. Is there anyone else who has been helpful to you who we have not mentioned?	

**Appendix G: Justifications & Validity of Graphic Symbols for each Measure**



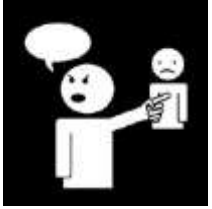
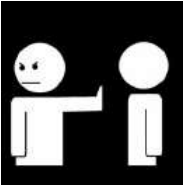


**Parental Stress Scale**

Item scale	Initial graphic symbol	Justification for use of graphic symbol	Comments from reviewer	Additional comments from researcher after reviewer's suggestion	Action taken for graphic symbol after reviewer's input
1. I am happy in my role as a caregiver of my grandchild with a disability.		This symbol was selected to illustrate being a caregiver	Use a full smiley face instead to illustrate the concept of "happy"	Agreed, new graphic symbol used to illustrate "happy"	
2. I would do whatever I can for my grandchild with a disability.		The concept of doing everything possible for the grandchild was illustrated by this symbol where the arrow points to the symbols within the circle illustrating "all"	Use picture from item 1 of PSS to show that the caregiver is supportive	Agreed, graphic symbol replaced with graphic symbol from item 1 of PSS	
3. Caring for my grandchild with a disability sometimes takes more time and energy than I have to give.		This symbol was used to illustrate the concept of time constraints further symbolised by the exclamation mark	Graphic symbol is correct for item	Agreed	No change to graphic symbol
4. I sometimes worry whether I am doing enough for my grandchild with a disability.		The concept of "worry" was illustrated in this symbol chosen due to the face looking strained with the hand on the forehead reinforced by the exclamation and question marks	Graphic symbol is correct for item	Agreed	No change to graphic symbol
5. I feel close to my grandchild with a disability.		The following symbol was chosen to illustrate the feeling of closeness by the hugging figures and the closeness illustrated by the figures	Rather replace this symbol with "love" picture in item 13 from PWBI to illustrate "love" and "closeness"	Agreed, graphic symbol replaced with the adult and child holding hands to represent closeness	




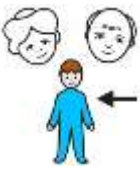

Item scale	Initial graphic symbol	Justification for use of graphic symbol	Comments from reviewer	Additional comments from researcher after reviewer's suggestion	Action taken for graphic symbol after reviewer's input
		of the adult and child playing together		further enhanced by the heart symbolising love	
6. I enjoy spending time with my grandchild with a disability.		This symbol was chosen to represent the adult and child doing a fun activity, such as singing, when spending time together	Use a graphic symbol where they are doing something together similar to item 5	Agreed	
7. My grandchild with a disability is an important source of love for me		This symbol was chosen due to the heart symbol to illustrate love	Rather use the illustration from item 8, and add heart eyes to illustrate "source of affection" or any symbol of a heart to show the concept of love	Agreed, graphic symbol replaced with symbol from item 8 adapted with the heart eyes indicating source of love	
8. Raising my grandchild with a disability gives me a more certain and positive view for the future.		This symbol was chosen as it illustrates the thought bubble with a smiling face in it representing a positive thought for the future	Rather use the progressing picture from item 7 of the PWBI here with added smiles to the three faces to represent positive future	Agreed: symbol replaced with the symbol illustrating the growing of the child, representing the future and	
9. The major source of stress in my life is my grandchild with a disability.		This symbol was used to illustrate the concept of stress	Graphic symbol is correct for item	Agreed	No change to graphic symbol

Item scale	Initial graphic symbol	Justification for use of graphic symbol	Comments from reviewer	Additional comments from researcher after reviewer's suggestion	Action taken for graphic symbol after reviewer's input
10. Raising my grandchild with a disability leaves little time and flexibility in my life.		This symbol was chosen due to the strained face illustrating the concept of being inflexible together with the time constraints represented by the various clocks	Graphic symbol is correct for item	Agreed	No change to graphic symbol
11. Raising my grandchild with a disability is a financial burden.		This symbol illustrated the concept of being financially strained by the red cross over the illustration of the money	Graphic symbol is correct for item	Agreed	No change to graphic symbol
12. It is difficult to balance different responsibilities because of my grandchild with a disability.		This symbol represented the concept of being engaged in many different responsibilities further heightened by the figures running showing difficulty with balancing the responsibilities	Graphic symbol is correct for item	Agreed	No change to graphic symbol
13. The behaviour of my grandchild with a disability is often stressful to me.		This illustration was used to characterise the bad or stressful behaviour of the child with the child running up the wrong end of the slide and the adult point a finger to the child as a warning	This symbol was used in the previous scale. Rather use a symbol containing a the child throwing something or look for a tantrum picture	Agreed, symbol changed to illustrate stressful behavior of grandchild	











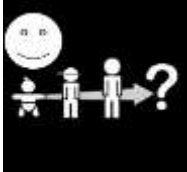



Item scale	Initial graphic symbol	Justification for use of graphic symbol	Comments from reviewer	Additional comments from researcher after reviewer's suggestion	Action taken for graphic symbol after reviewer's input
14. The behaviour of my grandchild with a disability is often embarrassing to me.		This symbol was selected due to the embarrassed face	The blushing from embarrassment is not very clear, rather use a symbol where the cheeks are red or darker to show embarrassment	Agreed, new symbol used to accentuate red cheeks representing embarrassment and also one that is more linked to skin colour will be used	
15. If I had it to do over again, I might decide not to raise my grandchild with a disability.		This symbol was selected as it illustrates the one figure shouting in protest and with an angry face which could be interpreted as not wanting to be a caregiver again	Rather use a symbol showing no	Agreed, new symbol used to illustrate no and never again	
16. I feel overwhelmed by the responsibility of being a parent to my grandchild with a disability.		This illustration was selected as it represents the figure's arms flapping and the speech bubble containing exclamation marks all of which convey the concept of being overwhelmed	Graphic symbol is correct for item	Agreed	No change to graphic symbol
17. Raising my grandchild with a disability has meant having too few choices.		This symbol was chosen as the question marks represent choices and the figure looking confused would illustrate the concept of having too few choices and not knowing what to do	Graphic symbol is correct for item	Agreed	No change to graphic symbol



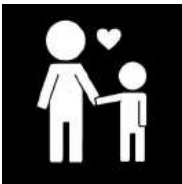







Item scale	Initial graphic symbol	Justification for use of graphic symbol	Comments from reviewer	Additional comments from researcher after reviewer's suggestion	Action taken for graphic symbol after reviewer's input
<p>18. Raising my grandchild with a disability has meant having too little control over my life.</p>		<p>This symbol was chosen as the figure holding its head represents the concept of feeling out of control</p>	<p>Rather use a picture illustrating a steering wheel to represent "control"</p>	<p>Disagreed: the steering wheel may confuse the participant. Rather an adapted symbol with an exclamation mark to illustrate frustration of lack of control together with a sad face will be used</p>	
<p>19. I am satisfied as a grandparent.</p>		<p>This symbol was chosen to represent the feeling of being satisfied due to the face's smile and thumbs up icon</p>	<p>Graphic symbol is correct for item</p>	<p>Agreed</p>	<p>No change to graphic symbol</p>
<p>20. I find my grandchild with a disability enjoyable.</p>		<p>This symbol was used as it contains the arrow pointing to the grandchild and the smiling faces of the older lady and man represent the grandparents</p>	<p>Graphic symbol is correct for item but if possible to find one with interaction with child is better</p>	<p>Agreed, symbol changed</p>	

**Personal Well-Being Index**




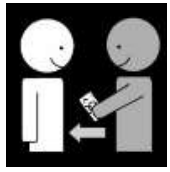
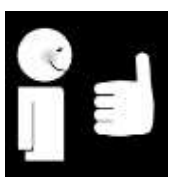
Item scale	Initial graphic symbol	Justification for use of graphic symbol	Comments from reviewer	Additional comments from researcher after reviewer's suggestion	Action taken for graphic symbol after reviewer's input
1. Since the beginning of the month you have felt that your life is going just great.		This symbol was chosen due to the smiling face coupled with the double thumbs up sign signifying happy, with further magnified with the two exclamation marks	Graphic symbol is correct for item	Agreed	No change to graphic symbol
2. Since the beginning of the month you have felt trapped by your responsibilities as a caregiver		This symbol was composed of a heart behind the bars of a cage to represent emotional entrapment	Graphic symbol is correct for item	Agreed	No change to graphic symbol
3. Since the beginning of the month you have found it easy to physically take care of your grandchild with a disability		This symbol was chosen as it represents a variety of physical activities to symbolise the context of "physically taking care" of the grandchild	Mind the cross in the picture. Rather either blank out the cross or use another picture	Agreed: Other picture will be used where there is no cross but still a variety of different activities being illustrated in the symbol	
4. Since the beginning of the month you have felt unwell or ill		This symbol was selected due to the illustration representing the concept of being sick or ill	Graphic symbol is correct for item	Agreed	No change to graphic symbol
5. Since the beginning of the month you have felt uneasy or scared without knowing why		This symbol represents the context of being scared and for an unknown reason (represented by the question mark)	Graphic symbol is correct for item	Agreed	No change to graphic symbol





Item scale	Initial graphic symbol	Justification for use of graphic symbol	Comments from reviewer	Additional comments from researcher after reviewer's suggestion	Action taken for graphic symbol after reviewer's input
6. Since the beginning of the month you have felt tired or exhausted-after caring for your grandchild with a disability		This item highlights the concept of being tired which was illustrated in this symbol by the closed eyes and unhappy face	Graphic symbol is correct for item	Agreed	No change to graphic symbol
7. Since the beginning of the month you have felt glad about your grandchild with a disability's future		This symbol was chosen to represent growth of the grandchild from a baby to an adult with the arrow as a timeline towards the question mark representing the future	Use a smiley face to represent the concept of "glad" instead of question mark	Picture was adapted with smiley face in the background to represent "glad" with the retaining of the question mark as a representation of "the future"	
8. Since the beginning of the month you have felt tired or run-down		This item represented the concept of physical tiredness here illustrated by the figure yawning and looking tired on the couch	This item is the same as item 6 consider keeping either 6 or 8	Keep both items because according to the dimensions being measured, this one is about the general well-being whereas item 6 is related to well-being due to caregiving	No change to graphic symbol
9. Since the beginning of the month you see no end to the demands your grandchild with a disability makes on you		This symbol was selected due to the figure pointing to the baby representing the grandchild and the question mark representing the no end to demands concept	Graphic symbol is correct for item	Agreed	No change to graphic symbol
10. Since the beginning of the month you have had lots of energy to get things done (e.g. household chores)		The concept of lots of energy to do chores was represented in this symbol where the figure is mopping, one of the common chores which requires energy to move around	Graphic symbol is correct for item	Agreed	No change to graphic symbol

Item scale	Initial graphic symbol	Justification for use of graphic symbol	Comments from reviewer	Additional comments from researcher after reviewer's suggestion	Action taken for graphic symbol after reviewer's input
11. Since the beginning of the month you have felt down or depressed		This symbol was chosen as it the face with the curved mouth closely represents “very sad” or “depressed” and together with the question mark indicating the unknown overall reason for “feeling down”	Graphic symbol is correct for item	Agreed	No change to graphic symbol
12. Since the beginning of the month you have had lots of energy to keep up with your grandchild with a disability.		This symbol was chosen because of the adult figure running after the child climbing up the unsafe side of the slide entails the adult needing energy to keep up with the child	Graphic symbol is correct for item	Agreed	No change to graphic symbol
13. Since the beginning of the month you have found pleasure in the things your grandchild with a disability does		This symbol was chosen due to the adult and child holding hands representing enjoyment	The heart icon in the symbol is may be seen to elude to love, maybe smiley face to represent “pleasure” and an illustration of doing an activity	Agreed, graphic symbol changed to illustrate doing an activity with smiling faces	
14. Since the beginning of the month you have felt very happy		The full face with eyes close when laughing was chosen as it illustrates the concept of being very happy	Graphic symbol is correct for item, but it will be better to have a person's face with skin colour	Agreed	

Item scale	Initial graphic symbol	Justification for use of graphic symbol	Comments from reviewer	Additional comments from researcher after reviewer's suggestion	Action taken for graphic symbol after reviewer's input
<p>15. Since the beginning of the month you find caring for your grandchild with a disability puts a strain on you</p>		<p>This symbol was chosen due to the sad face representing being unhappy and the thinking bubble filled with arrows mixed up in a bundle represent the mental stress</p>	<p>Use the couch picture from item 8 instead</p>	<p>Disagreed, keep same as this item refers to dimension of mental strain</p>	<p>No change to graphic symbol</p>
<p>16. Since the beginning of the month you have been feeling like you are in great shape</p>		<p>The concept of being in great shape is illustrated in this symbol by the various physical poses such as stretching jumping and walking, all representing the concept of being in good physical health</p>	<p>Graphic symbol is correct for item</p>	<p>Agreed</p>	<p>No change to graphic symbol</p>

### Support Functions Scale

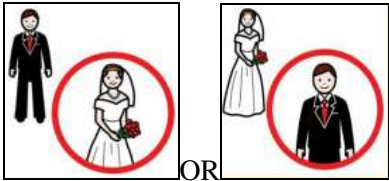



Item scale	Initial graphic symbol	Justification for use of graphic symbol	Comments from reviewer	Additional comments from researcher after reviewer's suggestion	Action taken for graphic symbol after reviewer's input
1. Someone to talk to about things that worry you		Symbol chosen due the sad face representing “worry” and the second figure in the symbol representing “another person”	Graphic symbol is correct for item	Agreed	No change to graphic symbol
2. Someone to help take care of your grandchild with a disability		The hands reaching out to the child represent the “help” concept while the hands may represent other persons as “someone”	Graphic symbol is correct for item	Agreed	No change to graphic symbol
3. Someone to talk to when you have questions about raising your grandchild with a disability		The two person figures were key concepts to represent “someone to talk to” and the question mark represented “questions”	Graphic symbol is correct for item	Agreed	No change to graphic symbol
4. Someone who can lend you money when you need it		This symbol was chosen as it represents the key concept of someone lending money	Graphic symbol is correct for item	Agreed	No change to graphic symbol
5. Someone to encourage or keep you going when things seem hard		The smiling figure in response to the “thumbs up” represents the concept of being motivated by others	Graphic symbol is correct for item	Agreed	No change to graphic symbol




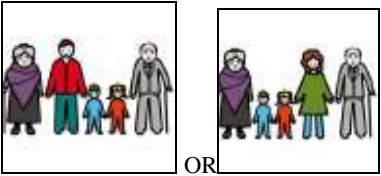
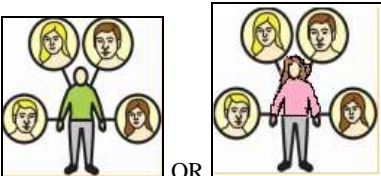
Item scale	Initial graphic symbol	Justification for use of graphic symbol	Comments from reviewer	Additional comments from researcher after reviewer's suggestion	Action taken for graphic symbol after reviewer's input
6. Someone who accepts your grandchild with a disability regardless of how he or she acts		This symbol was chosen for the depiction of many people in a circle represents a community, and the arrow towards the figure on the wheelchair represents inclusion and acceptance	Graphic symbol is correct for item	Agreed	No change to graphic symbol
7. Someone to help you with household chores		This symbol was chosen for the clear illustration of the various chores in the home	Graphic symbol is correct for item	Agreed	No change to graphic symbol
8. Someone you can relax or joke with		The two figures with the laughing face represent the relaxed and happy concept, while the one figure's hand on the shoulder of the other was indicating a friendly and familiar relationship	Graphic symbol is correct for item	Agreed	No change to graphic symbol
9. Someone to do things with your grandchild with a disability		This symbol was chosen due to the figures in the background which represents the concept of someone else other than the grandparent playing, or doing something with the grandchild	Graphic symbol is correct for item	Agreed	No change to graphic symbol

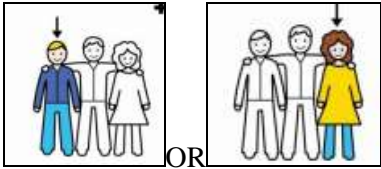

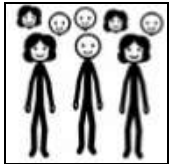







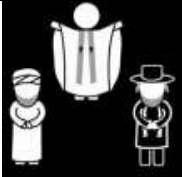



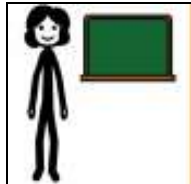


### Family Support Scale

Item scale	Initial graphic symbol	Justification for use of graphic symbol	Comments from reviewer	Additional comments from researcher after reviewer's suggestion	Action taken for graphic symbol after reviewer's input
1. How helpful has your husband/wife or partner been		This illustration was used due to the bride being circled to illustrate the concept of “wife” and the second picture where the groom is circled illustrating the “husband”	Graphic symbol is correct for item	Agreed	No change to graphic symbol
2. How helpful have your older child(ren) been		This symbol was found to be appropriate to represent the concept of “older child” due to the arrow pointing to the adult	Graphic symbol is correct for item	Agreed	No change to graphic symbol
3. How helpful have your neighbours been		This symbol clearly represents the concept of “living next door” as “neighbors”	Graphic symbol is correct for item	Agreed	No change to graphic symbol
4. How helpful have your parents been		This symbol was chosen to represent the parents of the grandparents illustrated by two old people in this symbol	Graphic symbol is correct for item	Agreed	No change to graphic symbol

Item scale	Initial graphic symbol	Justification for use of graphic symbol	Comments from reviewer	Additional comments from researcher after reviewer's suggestion	Action taken for graphic symbol after reviewer's input
5. Since the past 6 months how helpful have your other grandchildren have been		This symbol was used to illustrate the concept of other grandchildren	Graphic symbol is correct for item	Agreed	No change to graphic symbol
6. Since the past 6 months how helpful have your relatives been		This symbol represents the concept of relatives of the one grandparent	Graphic symbol is correct for item	Agreed	No change to graphic symbol
7. Since the past 6 months how helpful have your friends been		This symbol was used to represent the concept of friends of the one grandparent	Graphic symbol is correct for item	Agreed	No change to graphic symbol
8. Since the past 6 months how helpful have the parents of your husband/wife or partner been		These symbols were used to represent the parents of the husband and wife with both symbols having older persons with the man and lady figure	Graphic symbol is correct for item	Agreed	No change to graphic symbol
9. Since the past 6 months how helpful have the relatives of your husband/wife or partner been		These symbols were used to represent the relative if husband and of wife at the center of the genograms representing family ties	Graphic symbol is correct for item	Agreed	No change to graphic symbol

Item scale	Initial graphic symbol	Justification for use of graphic symbol	Comments from reviewer	Additional comments from researcher after reviewer's suggestion	Action taken for graphic symbol after reviewer's input
10. Since the past 6 months how helpful have the friends of your husband or partner been		These symbols were used to indicate friends of the husband and of the wife by the arrow pointing to the man for husband and to the lady for wife and the other figures representing the friends	Graphic symbol is correct for item	Agreed	No change to graphic symbol
11. Since the past 6 months how helpful has your nanny been		This symbol was used to illustrate the concept of “nanny” due to the figure of a lady next to the child and the figure of the adult waving at the two figures which would represent the grandparent leaving the child in the care of the nanny	Graphic symbol is correct for item	Agreed	No change to graphic symbol
12. Since the past 6 months how helpful have your co-workers been		This symbol was chosen to represent the concept of colleagues illustrated by the group of people	Graphic symbol is correct for item	Agreed	No change to graphic symbol
13. Since the past 6 months how helpful has your employer been		This symbol was used to represent the concept of an employer due to the red figure on the top of the genogram representing an employer	Graphic symbol is correct for item	Agreed	No change to graphic symbol

Item scale	Initial graphic symbol	Justification for use of graphic symbol	Comments from reviewer	Additional comments from researcher after reviewer's suggestion	Action taken for graphic symbol after reviewer's input
14. Since the past 6 months how helpful have other grandparents raising their grandchild with a disability been		This symbol was chosen to represent grandparent caregivers due to the baby figure being held by the older person in the symbol	Graphic symbol is correct for item	Agreed	No change to graphic symbol
15. Since the past 6 months how helpful have other grandparents been		The concept of other grandparents was represented by the older persons	Graphic symbol is correct for item	Agreed	No change to graphic symbol
16. Since the past 6 months how helpful have members of grandparent caregivers support group been		This symbol was used to represent the concept of a support group	Graphic symbol is correct for item	Agreed	No change to graphic symbol
17. Since the past 6 months how helpful have members of your social groups/clubs been		This symbol was chosen due to the figures seeming to discuss a matter as a group	Graphic symbol is correct for item	Agreed	No change to graphic symbol
18. Since the past 6 months how helpful have your fellow religious group members or spiritual leaders been		This symbol was chosen as it clearly illustrates the concept of faith leaders	Graphic symbol is correct for item	Agreed	No change to graphic symbol

Item scale	Initial graphic symbol	Justification for use of graphic symbol	Comments from reviewer	Additional comments from researcher after reviewer's suggestion	Action taken for graphic symbol after reviewer's input
19. Since the past 6 months how helpful have professional helpers (e.g. social worker, community rehab worker, therapists) been		This symbol was chosen as it represents the rehabilitation professionals with further illustration therapy types illustrated between the two figures	Graphic symbol is correct for item	Agreed	No change to graphic symbol
20. Since the past 6 months how helpful has your grandchild with a disability's care centres/crèche been		This symbol was found to be appropriate to represent the concept of teacher due to the blackboard in the background and the figure of the lady as the teacher	Graphic symbol is correct for item	Agreed	No change to graphic symbol
21. Since the past 6 months how helpful has your family doctor or the doctor of your grandchild with a disability been		This symbol was chosen as it clearly illustrated the concept of doctor of the grandchild with the figure of the doctor performing a health check on the child	Graphic symbol is correct for item	Agreed	No change to graphic symbol
22. Since the past 6 months how helpful have professional helpers at your local clinic (e.g. community health worker and nurses) been		This illustration was chosen as it represents the overall concept of community health workers and nurses who are found at the local clinics	Graphic symbol is correct for item	Agreed	No change to graphic symbol

### Appendix H1: Section A of Survey (English)

Participant Code: \_\_\_\_\_

INSTRUCTION: These questions are give us information about you, and your grandchild(ren) who has a disability. For this study, your family is anyone who lives in the same household, who support and care for each other every day and who think of themselves as part of your family. They may or may not be related by blood.

#### 1. ABOUT YOU

1.1. What is your age? \_\_\_\_\_

G1

1.2. What is your first language (*mark with X*):

(X)

isiXhosa  
Afrikaans  
English

G2
G3
G4

1.3. What is your relationship with the child with a disability (*mark with X*):

(X)

Grandmother  
Grandfather

G5
G6

1.4. Do you have any medical health problems (*mark with X*):

(X)

Diabetes  
Hypertension  
Arthritis  
Other

G7
G8
G9
G10

1.5. What is your highest education level? \_\_\_\_\_

G11

#### 2. ABOUT YOUR GRANDCHILD WITH A DISABILITY, YOUR HOUSEHOLD & FINANCIAL SITUATION

2.1. How long have you been raising your grandchild with a disability? \_\_\_\_

G12

2.2. What happened that you had to raise your grandchild with a disability:

\_\_\_\_\_

G13

\_\_\_\_\_

G14

2.3. What is the gender of your grandchild who has a disability and what is their age?

<b>(X)</b>		<b>Age</b>	
	Boy	<b>G15</b>	<b>G16</b>
	Girl	<b>G17</b>	<b>G18</b>

2.4. Who are the people living with you and do they work (*mark with X*):

<b>(X)</b>		<b>Ages</b>	<b>Working</b>	<b>Contribute to finances</b>
	Grandchild with a disability's mother	<b>G19</b>	Yes/No	<b>G29</b> Yes/No <b>G35</b>
	Grandchild with a disability's father	<b>G21</b>	Yes/No	<b>G30</b> Yes/No <b>G36</b>
	Grandchild with a disability's brother	<b>G23</b>	Yes/No	<b>G31</b> Yes/No <b>G37</b>
	Grandchild with a disability's sister	<b>G25</b>	Yes/No	<b>G32</b> Yes/No <b>G38</b>
	Number of other older children: _____		Yes/No	<b>G33</b> Yes/No <b>G39</b>
	Other relatives/people in household: _____		Yes/No	<b>G34</b> Yes/No <b>G40</b>

Total number of people living in the household: _____	<b>G41</b>
Total number of people working in the household: _____	<b>G42</b>
Total number of people contributing to the household: _____	<b>G43</b>

2.5. How would you describe your family's financial situation? (*Mark with X*):

<b>(X)</b>		
	We do not have enough money left at the end of the month and we are struggling	<b>G44</b>
	We just get by at the end of the month	<b>G45</b>
	We have a little money left at the end of the month	<b>G46</b>

2.6. How much money would you say comes into the family at the end of the month? (*Mark with X*)

<b>(X)</b>		
	R 500 – R 1000	<b>G47</b>
	R 1050 – R 2000	<b>G48</b>
	R 2050 – R 3000	<b>G49</b>
	R 3050 – R 4500	<b>G50</b>
	More than R 4500	<b>G51</b>

2.7. Where do you get your money from (mark with X, more than one if applicable):

<input checked="" type="checkbox"/>		
<input type="checkbox"/>	Employed full-time	G52
<input type="checkbox"/>	Employed part-time/ Casual	G53
<input type="checkbox"/>	Unemployed	G54
<input type="checkbox"/>	Self employed	G55
<input type="checkbox"/>	Retired	G56
<input type="checkbox"/>	Grant receiver	G57
<input type="checkbox"/>	Pension	G58
<input type="checkbox"/>	Other _____	G59

**3. Ten Questions**

<b>3. Ten Questions</b>			Yes	No	
<i>For the Interviewer: The questionnaire result is positive if the response to any one or more of the Ten Questions has an asterisk (*) next to it. If no has (*) next to it then the result is negative (child meets selection criteria for the study).</i>					
<b>G60</b>	Compared with other children, did (name of child) have any serious delay in sitting, standing or walking?	*			
<b>G61</b>	Compared with other children, does (name of child) have difficulty seeing either in the daytime or at night?	*			
<b>G62</b>	Does (name of child) appear to have difficulty hearing?	*			
<b>G63</b>	When you tell (name of child) to do something, does he/she see to understand what you are saying?			*	
<b>G64</b>	Does (name of child) have difficulty in walking or moving his/her arms or does he/she have weakness and/or stiffness in the arms or legs?	*			
<b>G65</b>	Does (name of child) sometimes have fits, become ridged, or lose consciousness?	*			
<b>G66</b>	Does (name of child) learn to do things like other children his/her age?			*	
<b>G67</b>	Does (name of child) speak at all (can he/she make himself/herself understood in the words; can he/she say recognizable words)?			*	
<b>G68</b>	For 3 to 9 year-old children ask: Is (name of child)'s speech in any way different from normal (not clear enough to be understood by people other than his/her immediate family)?	*			
<b>G69</b>	For 2 year old children ask: can he/she name at least one object (for example, an animal, a toy, a cup, a spoon)?			*	
<b>G70</b>	Compared with other children of his/her age, does (name of child) appear in any way mentally backward, dull or slow?	*			
<b>G71</b>	<i>Does child meets selection criteria?</i>				



## Appendix H2: Section A of Survey (IsiXhosa)

Participant Number: \_\_\_\_\_

**INSTRUCTIONS:** Le mibuzo ingolwazi ngawe, nomzukulwana okanye abazukulwana bakho abakhubazekileyo. Kolu phando, usapho lwakho nguye nabani nha ohlala edlini nawe, umntu enikhathaleleneyo mihla nemihla, nabazibona belusapho lwakho. Isenokwenzeka anizalani, okanye ayilogazi lakho.

### ABOUT YOU (Ngawe)

1. Mingaphi iminyaka kakho? \_\_\_\_\_ G1
  
2. Loluphi ulwimi lwakho lokuqala? (Mark with **X**):
 

<input checked="" type="checkbox"/>		
<input type="checkbox"/>	isiXhosa	G2
<input type="checkbox"/>	isiBhulu	G3
<input type="checkbox"/>	isiNgesi	G4
  
3. Ulwalamane (nizalana njani) njani nomntana okhubazekileyo? (Mark with **X**):
 

<input checked="" type="checkbox"/>		
<input type="checkbox"/>	Makhulu	G5
<input type="checkbox"/>	Tatomkhulu	G6
  
4. Unazo ingxaki nempilo yakho? (Mark with **X**):
 

<input checked="" type="checkbox"/>		
<input type="checkbox"/>	i-Diabetes	G7
<input type="checkbox"/>	i-Hypertension	G8
<input type="checkbox"/>	i-Arthritis	G9
<input type="checkbox"/>	Enye	G10
  
5. Wagqiba kubani esikolweni? \_\_\_\_\_ G11

### MALUNGA NABANTWANA BAKHO ABAKHUBAZEKILEYO, UMZI WAKHO NEMALI

6. Unexesha elingakanani ukhulisa umzukulwana wakho okhubazekileyo? \_\_\_\_\_ G12

7. Yintoni eyabangela ukuba ukhulise umzukulwana wakho okhubazekileyo?

\_\_\_\_\_ G13

\_\_\_\_\_ G14

8. Usesiphi isini umzululwana wakho okhubazekileyo kwaye unangaphi?

<b>(X)</b>			<b>Iminyaka</b>	
	Inkwenkwe	<b>G15</b>		<b>G16</b>
	Intombi	<b>G17</b>		<b>G18</b>

9. Ngobani abahlala kunye nawe ingaba bayasebenza? (mark with **X**) :

<b>(X)</b>		<b>Ages</b>		<b>Working</b>	<b>Contribute to finances</b>			
	Umama womzukulwana okhubazekileyo	<b>G19</b>		<b>G20</b>	Ewe/hayi	<b>G29</b>	Ewe/hayi	<b>G35</b>
	Utata womzukulwana okhubazekileyo	<b>G21</b>		<b>G22</b>	Ewe/hayi	<b>G30</b>	Ewe/hayi	<b>G36</b>
	Unakwabo umzukulwana okhubazekileyo	<b>G23</b>		<b>G24</b>	Ewe/hayi	<b>G31</b>	Ewe/hayi	<b>G37</b>
	Udade wakhe umzukulwana okhubazekileyo	<b>G25</b>		<b>G26</b>	Ewe/hayi	<b>G32</b>	Ewe/hayi	<b>G38</b>
	Inani lwabanye abantwana: _____			<b>G27</b>	Ewe/hayi	<b>G33</b>	Ewe/hayi	<b>G39</b>
	Abanye abantu/isizalwana enihlala naso endlini: _____			<b>G28</b>	Ewe/hayi	<b>G34</b>	Ewe/hayi	<b>G40</b>

Inani elipheleleyo lwabantu abahlala endlini: _____	<b>G41</b>
Inani elipheleleyo lwabantu abaphangelayo endlini: _____	<b>G42</b>
Inani elipheleleyo lwabantu abancedisayo endlini: _____	<b>G43</b>

10. Ungayicacisa njani imeko yemali endlini yakho? (mark with **X**):

<b>(X)</b>		
	Asibinayo imali eyoneleyo ukuphela kwenyanga, siyasokola	<b>G44</b>
	Siye sifike ekupheleni kwenyanga	<b>G45</b>
	Sibanayo imali encinci ukuphela kwenyanga	<b>G46</b>

11. Ungathi kungena ,malini kusapho lwakho ukuphela kwenyanga? (mark with **X**)

<b>(X)</b>		
	R 500 – R 1000	<b>G47</b>
	R 1050 – R 2000	<b>G48</b>
	R 2050 – R 3000	<b>G49</b>
	R 3050 – R 4500	<b>G50</b>
	Ngaphezu kwe- R 4500	<b>G51</b>

12. Uyifumana phi imali yakho (Faka u- **X**, nokuba ngezingaphi apho unyanzelekile:

<b>(X)</b>		
	Uphangela isigxina	<b>G52</b>
	Umana uphangela ngalomaxesha	<b>G53</b>
	Awuphangeli	<b>G54</b>
	Uziqeshile	<b>G55</b>
	Uthathe umhlala phantsi	<b>G56</b>
	Ufumana igranti	<b>G57</b>
	Udla umhlala phantsi	<b>G58</b>
	Enye _____	<b>G59</b>

**Ten Questions Screening Tool**

*For the Interviewer: The questionnaire result is positive if the response to any one or more of the Ten Questions has an asterisk (\*) next to it. If no has (\*) next to it then the result is negative (child meets selection criteria for the study).*

		Ewe	Hayi
<b>G60</b>	Thelekisa nabanye abantwana, ukuba (igama lomntana) ukhe walibaziseka ekwazini ukuhlala, ukuma,okanye ukuhamba?	*	
<b>G61</b>	Thelekisa nabanye abantwana, ukuba (igama lomntana) ebenengxaki ukubona emini okanye ebusuku?	*	
<b>G62</b>	(igama lomntana) ungathi unayo ingxaki yongeva ngendlebe?	*	
<b>G63</b>	Xa umxelela (igama lomntana) ukuba makenze into, uyayiqonda lento uyithethayo?		*
<b>G64</b>	(igama lomntana) uyoyisakala ukuhamba ukushukumisa iingalo okanye unokoyisakala ezingalweni nasemilenzeni?	*	
<b>G65</b>	(igama lomntana) uamaxesha axhuzule, ome umzimba lo okanye angabikho sezingqondweni?	*	
<b>G66</b>	(igama lomntana) ufunda ukwenza izinto njengabanye abantwana abangontanga bakhe?		*
<b>G67</b>	(igama lomntana) akakhwazi ukuthetha (uyakwazi ukuzenza aqondwe ukuba uthini ngaloo magama athile; uthetha amagama aqondakalayo?		*
<b>G68</b>	<i>For 3 to 9 year-old children ask:</i> (igama lomntana) indlela athetha ngayo yohlukile kwezinye indlela ekuthethwa ngazo (ayivakali kakuhle ukuba ingaqondwa ngabanye abantu abangelosapho lwakhe)?	*	
<b>G69</b>	<i>For 2 year old children ask:</i> uyakwazi ubiza into enye (umzekelo, isilwanyana esithile, into yodlala, ikomityi, okanye ispuni)?		*
<b>G70</b>	Thelekisa nabanye abantwana abazintanga zakhe, (igama lomntana) ukhangeleka ingathi usemva ngokwengqondo, uthatha kade, utsalanzima ngokokucinga?	*	
<b>G71</b>	<i>Does the child meet the selection criteria?</i>		

### Appendix H3: Section A of Survey (Afrikaans)

Participant Number: \_\_\_\_\_

**INSTRUCTIONS:** Hierdie vrae gaan oor inligting oor u en u gestremde kleinkind(ers). Vir hierdie studie is u familie enigiemand wat in dieselfde huishouding woon, wat elke dag mekaar ondersteun en vir mekaar omgee en wat hulself as deel van u familie beskou. Hierdie mense is nie noodwendig bloedverwante nie.

#### U INLIGTING

1. Wat is u ouderdom? \_\_\_\_\_ G1
  
2. Wat is u moedertaal (mark with **X**):
 

<b>(X)</b>		
	isiXhosa	G2
	Afrikaans	G3
	English	G4
  
3. Wat is u verhouding met die gestremde kleinkind (mark with **X**):
 

<b>(X)</b>		
	Ouma	G5
	Oupa	G6
  
4. Het u enige mediese gesondheidsprobleme (mark with **X**):
 

<b>(X)</b>		
	Diabeet	G7
	Hoë bloeddruk	G8
	Artritis	G9
	Ander _____	G10
  
5. Wat is u hoogste vlak van opvoeding? \_\_\_\_\_ G11

#### INLIGTING OOR U GESTREMDE KLEINKIND, U HUISHOUDING EN FINANSIËLE SITUASIE

6. Vir hoe lank maak u al u gestremde kleinkind groot? \_\_\_\_\_ G12
  
7. Wat het gebeur dat u u gestremde kleinkind moet grootmaak:
 

	G13
	G14

8. Wat is die geslag en ouderdom van u gestremde kleinkind?

<b>(X)</b>		<b>Ouderdom</b>	
	Seun	<b>G15</b>	<b>G16</b>
	Meisie	<b>G17</b>	<b>G18</b>

9. Wie is die mense wat saam met u woon? Werk hulle (mark with **X**) :

<b>(X)</b>		<b>Ouderdomme</b>	<b>Werk</b>	<b>Dra by tot finansies</b>
	Gestremde kleinkind se ma	<b>G19</b>	<b>G20</b>	Ja/Nee <b>G29</b>
	Gestremde kleinkind se pa	<b>G21</b>	<b>G22</b>	Ja/Nee <b>G30</b>
	Gestremde kleinkind se broer	<b>G23</b>	<b>G24</b>	Ja/Nee <b>G31</b>
	Gestremde kleinkind se suster	<b>G25</b>	<b>G26</b>	Ja/Nee <b>G32</b>
	Aantal ander ouer kinders: _____		<b>G27</b>	Ja/Nee <b>G33</b>
	Ander familie/mense in die huishouding: _____		<b>G28</b>	Ja/Nee <b>G34</b>

Totale aantal mense wat in die huishouding woon: _____	<b>G41</b>
Totale aantal mense in die huishouding wat werk: _____	<b>G42</b>
Totale aantal mense wat tot die huishouding bydra: _____	<b>G43</b>

10. Hoe sal u u familie se finansiële situasie beskryf? (mark with **X**):

<b>(X)</b>		
	Ons het nie aan die einde van die maand genoeg geld oor nie en ons sukkel	<b>G44</b>
	Ons kom net-net deur die einde van die maand	<b>G45</b>
	Ons het 'n bietjie geld oor aan die einde van die maand	<b>G46</b>

11. Hoeveel geld sou u sê kom na die familie toe aan die einde van die maand? (mark with **X**)






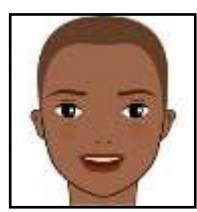



<b>(X)</b>		
	R 500 – R 1000	<b>G47</b>
	R 1050 – R 2000	<b>G48</b>
	R 2050 – R 3000	<b>G49</b>
	R 3050 – R 4500	<b>G50</b>
	Meer as R 4500	<b>G51</b>





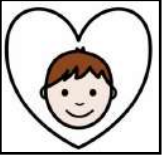


12. Waar kry u u geld vandaan (mark with **X**, more than one option is acceptable):

<input checked="" type="checkbox"/>		
<input type="checkbox"/>	Werk voltyds	<b>G52</b>
<input type="checkbox"/>	Werk deelyds	<b>G53</b>
<input type="checkbox"/>	Werkloos	<b>G54</b>
<input type="checkbox"/>	Entrepreneur	<b>G55</b>
<input type="checkbox"/>	Afgetree	<b>G56</b>
<input type="checkbox"/>	Ontvang toelae	<b>G57</b>
<input type="checkbox"/>	Pensioen	<b>G58</b>
<input type="checkbox"/>	Ander _____	<b>G59</b>





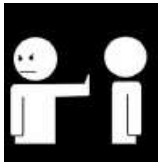


<b>Ten Questions Screening Tool</b>		Ja	Nee
<i>For the Interviewer: The questionnaire result is positive if the response to any one or more of the Ten Questions has an asterisk (*) next to it. If no has (*) next to it then the result is negative (child meets selection criteria for the study).</i>			
<b>G60</b>	In vergelyking met ander kinders, het (naam van kind) enige ernstige agterstand gehad in sit, staan of loop?	*	
<b>G61</b>	In vergelyking met ander kinders, het (naam van kind) enige ernstige agterstand gehad om te sien (bedags of snags)?	*	
<b>G62</b>	Lyk dit asof (naam van kind) moeilik hoor?	*	
<b>G63</b>	Wanneer u vir (naam van kind) vra om iets te doen, verstaan hy/sy wat u sê?		*
<b>G64</b>	Is dit vir (naam van kind) moeilik om te loop of om sy/haar arms te beweeg of het hy/sy enige swakheid en/of styfheid in die arms of bene?	*	
<b>G65</b>	Kry (naam van kind) soms aanvalle, word styf of verloor sy/haar bewussyn?	*	
<b>G66</b>	Leer (naam van kind) om dinge te doen soos ander kinders van sy/haar ouderdom?		*
<b>G67</b>	Praat (naam van kind) hoegenaamd (kan hy/sy hom-/haarself in woorde verstaanbaar maak; kan hy/sy herkenbare woorde sê)?		*
<b>G68</b>	<i>For 3 to 9 year-old children ask:</i> Is (naam van kind) se spraak op enige manier anders as normaal (nie duidelik genoeg om verstaanbaar te wees vir ander mense as sy/haar onmiddellike familie nie)?	*	
<b>G69</b>	<i>For 2 year old children ask:</i> kan hy/sy ten minste een voorwerp benoem (byvoorbeeld 'n dier, 'n speelding, 'n beker, 'n lepel)?		*
<b>G70</b>	In vergelyking met ander kinders van sy/haar ouderdom, lyk dit asof (naam van kind) op enige manier verstandelik agter is, bietjie stadig of vaag voorkom?	*	
<b>G71</b>	<i>Does the child meet the selection criteria?</i>		



**Appendix I 1: Interviewer’s Side of Booklet for Each Measure (English)**







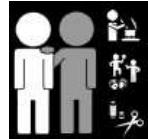


<b>PARENTAL STRESS SCALE</b>	
<p><b>INSTRUCTIONS:</b> “We will now look at how you feel about being a caregiver and measure how much stress you experience as caregiver. For each of these sentences think about how your relationship is with your grandchild who has a disability. So that we can measure how you experience the stress of raising your grandchild, we look at how much agree or disagree with the sentences we will read to you. This picture means you strongly agree, this one means you agree, this one means you disagree and this one means you strongly disagree”.</p>	
1	2
	
Strongly disagree	Disagree
3	4
	
Undecided	Agree
5	
	
Strongly agree	
1.	<p>You are happy in your role as a caregiver of your grandchild with a disability</p> <p><i>Score:</i>                      1 Strongly disagree                      2 Disagree                      3 Undecided                      4 Agree                      5 Strongly agree</p>
	
2.	<p>You would do everything you can for your grandchild with a disability</p> <p><i>Score:</i>                      1 Strongly disagree                      2 Disagree                      3 Undecided                      4 Agree                      5 Strongly agree</p>
	
3.	<p>Caring for your grandchild with a disability sometimes takes more time and energy than you have to give.</p> <p><i>Score:</i>                      1 Strongly disagree                      2 Disagree                      3 Undecided                      4 Agree                      5 Strongly agree</p>
	
4.	<p>Raising your grandchild with a disability has meant having too little control over your own life.</p> <p><i>Score:</i>                      1 Strongly disagree                      2 Disagree                      3 Undecided                      4 Agree                      5 Strongly agree</p>
	


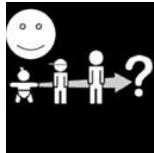





<p>5.</p>	<p>You sometimes worry whether you are doing enough for your grandchild with a disability</p> <p><i>Score:</i>            1 Strongly disagree            2 Disagree            3 Undecided            4 Agree            5 Strongly agree</p>	
<p>6.</p>	<p>The behaviour of your grandchild with a disability is often stressful to you</p> <p><i>Score:</i>            1 Strongly disagree            2 Disagree            3 Undecided            4 Agree            5 Strongly agree</p>	
<p>7.</p>	<p>You feel close to your grandchild with a disability</p> <p><i>Score:</i>            1 Strongly disagree            2 Disagree            3 Undecided            4 Agree            5 Strongly agree</p>	
<p>8.</p>	<p>You enjoy spending time with your grandchild with a disability</p> <p><i>Score:</i>            1 Strongly disagree            2 Disagree            3 Undecided            4 Agree            5 Strongly agree</p>	
<p>9.</p>	<p>Your grandchild with a disability is an important source of love for you</p> <p><i>Score:</i>            1 Strongly disagree            2 Disagree            3 Undecided            4 Agree            5 Strongly agree</p>	
<p>10.</p>	<p>Raising your grandchild with a disability gives you a more certain and positive view for the future</p> <p><i>Score:</i>            1 Strongly disagree            2 Disagree            3 Undecided            4 Agree            5 Strongly agree</p>	
<p>11.</p>	<p>The major source of stress in your life is your grandchild with a disability</p> <p><i>Score:</i>            1 Strongly disagree            2 Disagree            3 Undecided            4 Agree            5 Strongly agree</p>	
<p>12.</p>	<p>Raising your grandchild with a disability leaves little time and flexibility in your life</p>	










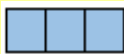



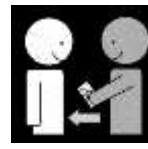

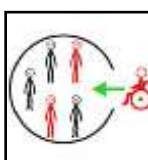
	<p><i>Score:</i>                      1 Strongly disagree                      2 Disagree                      3 Undecided                      4 Agree                      5 Strongly agree</p>	
13.	<p>Raising your grandchild with a disability is a financial burden</p> <p><i>Score:</i>                      1 Strongly disagree                      2 Disagree                      3 Undecided                      4 Agree                      5 Strongly agree</p>	
14.	<p>It is difficult to balance different responsibilities because of your grandchild with a disability</p> <p><i>Score:</i>                      1 Strongly disagree                      2 Disagree                      3 Undecided                      4 Agree                      5 Strongly agree</p>	
15.	<p>The behaviour of your grandchild with a disability is often embarrassing to you</p> <p><i>Score:</i>                      1 Strongly disagree                      2 Disagree                      3 Undecided                      4 Agree                      5 Strongly agree</p>	
16.	<p>If you had it to do over again, you might decide not to raise your grandchild with a disability</p> <p><i>Score:</i>                      1 Strongly disagree                      2 Disagree                      3 Undecided                      4 Agree                      5 Strongly agree</p>	
17.	<p>You feel overwhelmed by the responsibility of being a caregiver to your grandchild with a disability</p> <p><i>Score:</i>                      1 Strongly disagree                      2 Disagree                      3 Undecided                      4 Agree                      5 Strongly agree</p>	
18.	<p>Raising your grandchild with a disability has meant having too few choices</p> <p><i>Score:</i>                      1 Strongly disagree                      2 Disagree                      3 Undecided                      4 Agree                      5 Strongly agree</p>	







<p>19.</p>	<p>You are satisfied as a grandparent</p> <p><i>Score:</i></p> <p>1 Strongly disagree</p> <p>2 Disagree</p> <p>3 Undecided</p> <p>4 Agree</p> <p>5 Strongly agree</p>	
<p>20.</p>	<p>You find your grandchild with a disability enjoyable</p> <p><i>Score:</i></p> <p>1 Strongly disagree</p> <p>2 Disagree</p> <p>3 Undecided</p> <p>4 Agree</p> <p>5 Strongly agree</p>	




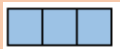





<b>PERSONAL WELL-BEING INDEX</b>	
<p><b>INSTRUCTIONS:</b> “Now we are going to look at your well-being, and we will try to measure how often it happens, like how often do you feel tired or how often do you feel happy. This ranges from ‘You never feel like this’ to ‘You often feel this’”. This picture means you ‘never feel like this’, this one means ‘you felt this once in a while’, this means that ‘you sometimes felt this’ and this one means ‘you often felt this’. Think about how you have felt since the beginning of the month/last two weeks when raising your grandchild with a disability”</p>	
<p>1</p>  <p>You never felt like this</p>	<p>2</p>  <p>You felt this once in a while</p>
<p>3</p>  <p>You sometimes felt this</p>	<p>4</p>  <p>You often felt this</p>
<p>1.</p>	<p>Since the beginning of the month/past 2 weeks how often have you felt that your life is going just great</p> <p><i>Score:</i></p> <p>1 You never felt like this 2 You felt this once in a while 3 You sometimes felt this 4 You often felt this</p> 
<p>2.</p>	<p>Since the beginning of the month/past 2 weeks how often have you felt trapped by your responsibilities as a caregiver of your grandchild with a disability</p> <p><i>Score:</i></p> <p>1 You never felt like this 2 You felt this once in a while 3 You sometimes felt this 4 You often felt this</p> 
<p>3.</p>	<p>Since the beginning of the month/past 2 weeks how often have you found it easy to physically take care of your grandchild with a disability</p> <p><i>Score:</i></p> <p>1 You never felt like this 2 You felt this once in a while 3 You sometimes felt this 4 You often felt this</p> 
<p>4.</p>	<p>Since the beginning of the month/past 2 weeks how often have you felt unwell or ill</p> <p><i>Score:</i></p> <p>1 You never felt like this 2 You felt this once in a while 3 You sometimes felt this 4 You often felt this</p> 
<p>5.</p>	<p>Since the beginning of the month/past 2 weeks how often have you felt uneasy or scared without knowing why</p> <p><i>Score:</i></p> <p>1 You never felt like this 2 You felt this once in a while 3 You sometimes felt this 4 You often felt this</p> 

<p>6.</p>	<p>Since the beginning of the month/past 2 weeks how often have you felt tired or exhausted after caring for your grandchild with a disability</p> <p><i>Score:</i>            1 You never felt like this            2 You felt this once in a while            3 You sometimes felt this            4 You often felt this</p>	
<p>7.</p>	<p>Since the beginning of the month/past 2 weeks how often have you felt glad about your grandchild with a disability's future</p> <p><i>Score:</i>            1 You never felt like this            2 You felt this once in a while            3 You sometimes felt this            4 You often felt this</p>	
<p>8.</p>	<p>Since the beginning of the month/past 2 weeks how often have you felt tired or run-down</p> <p><i>Score:</i>            1 You never felt like this            2 You felt this once in a while            3 You sometimes felt this            4 You often felt this</p>	
<p>9.</p>	<p>Since the beginning of the month/past 2 weeks how often have you seen no end to the demands your grandchild with a disability makes on you</p> <p><i>Score:</i>            1 You never felt like this            2 You felt this once in a while            3 You sometimes felt this            4 You often felt this</p>	
<p>10.</p>	<p>Since the beginning of the month/past 2 weeks how often have you had lots of energy to get things done (e.g. household chores)</p> <p><i>Score:</i>            1 You never felt like this            2 You felt this once in a while            3 You sometimes felt this            4 You often felt this</p>	
<p>11.</p>	<p>Since the beginning of the month/past 2 weeks how often have you felt down or depressed</p> <p><i>Score:</i>            1 You never felt like this            2 You felt this once in a while            3 You sometimes felt this            4 You often felt this</p>	
<p>12.</p>	<p>Since the beginning of the month/past 2 weeks how often have you had lots of energy to keep up with your grandchild with a disability</p> <p><i>Score:</i>            1 You never felt like this            2 You felt this once in a while            3 You sometimes felt this            4 You often felt this</p>	



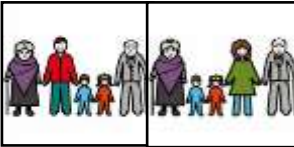
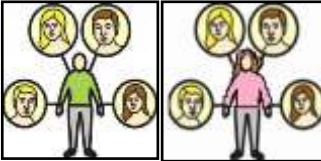
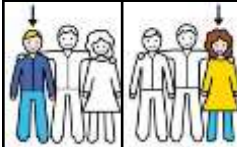


13.	<p>Since the beginning of the month/past 2 weeks how often have you found pleasure in the things your grandchild with a disability does</p> <p><i>Score:</i></p> <p>1 You never felt like this  2 You felt this once in a while  3 You sometimes felt this  4 You often felt this</p>	
14.	<p>Since the beginning of the month/past 2 weeks how often have you felt really happy</p> <p><i>Score:</i></p> <p>1 You never felt like this  2 You felt this once in a while  3 You sometimes felt this  4 You often felt this</p>	
15.	<p>Since the beginning of the month/past 2 weeks how often have you found that caring for your grandchild with a disability puts a strain on you</p> <p><i>Score:</i></p> <p>1 You never felt like this  2 You felt this once in a while  3 You sometimes felt this  4 You often felt this</p>	
16.	<p>Since the beginning of the month/past 2 weeks how often have you been feeling like you are in great shape</p> <p><i>Score:</i></p> <p>1 You never felt like this  2 You felt this once in a while  3 You sometimes felt this  4 You often felt this</p>	








<b>SUPPORT FUNCTIONS SCALE</b>			
<b>INSTRUCTIONS:</b> “Now we will look at the types of support which you need and how often you need this help. To measure what types of supports you need, it varies from ‘You never need this help’ to ‘You need this help quite often’. This picture is for when you ‘never need this help’, this one is for when you ‘need this help once in a while’, this picture is for when you ‘sometimes need this help’ and this one is for when you ‘quite often need this help’.”			
1	2	3	4
 You never need this help	 You need this help once in a while	 You sometimes need this help	 You need this help quite often
1.	How often do you feel you need someone to talk to about things that worry you <i>Score:</i> 1 You never need this help 2 You need this help once in a while 3 You sometimes need this help 4 You need this help quite often		
2.	How often do you feel you need someone to help take care of your grandchild with a disability <i>Score:</i> 1 You never need this help 2 You need this help once in a while 3 You sometimes need this help 4 You need this help quite often		
3.	How often do you feel you need someone to talk to when you have questions about raising your grandchild with a disability <i>Score:</i> 1 You never need this help 2 You need this help once in a while 3 You sometimes need this help 4 You need this help quite often		
4.	How often do you feel you need someone who can lend you money when you need it <i>Score:</i> 1 You never need this help 2 You need this help once in a while 3 You sometimes need this help 4 You need this help quite often		
5.	How often do you feel you need someone to encourage or keep you going when things seem hard <i>Score:</i> 1 You never need this help 2 You need this help once in a while 3 You sometimes need this help 4 You need this help quite often		
6.	How often do you feel you need someone who accepts your grandchild with a disability regardless of how he or she acts <i>Score:</i> 1 You never need this help 2 You need this help once in a while 3 You sometimes need this help 4 You need this help quite often		

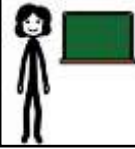


<p>7.</p>	<p>How often do you feel you need someone to help you with household chores</p> <p><i>Score:</i></p> <p>1 You never need this help                  2 You need this help once in a while                  3 You sometimes need this help                  4 You need this help quite often</p>	
<p>8.</p>	<p>How often do you feel you need someone with whom you can relax or laugh with</p> <p><i>Score:</i></p> <p>1 You never need this help                  2 You need this help once in a while                  3 You sometimes need this help                  4 You need this help quite often</p>	
<p>9.</p>	<p>How often do you feel you need someone to do things with your grandchild with a disability</p> <p><i>Score:</i></p> <p>1 You never need this help                  2 You need this help once in a while                  3 You sometimes need this help                  4 You need this help quite often</p>	
<p>10.</p>	<p>How often do you feel you need someone to help your grandchild with a disability or you with transportation</p> <p><i>Score:</i></p> <p>1 You never need this help                  2 You need this help once in a while                  3 You sometimes need this help                  4 You need this help quite often</p>	
<p>11.</p>	<p>How often do you feel you need someone to follow up with SASSA (e.g. grants) or hospital services (e.g. therapy/doctor appointments) when you can't</p> <p><i>Score:</i></p> <p>1 You never need this help                  2 You need this help once in a while                  3 You sometimes need this help                  4 You need this help quite often</p>	
<p>12.</p>	<p>How often do you feel you need someone who can tell you about services for your grandchild with a disability or your family</p> <p><i>Score:</i></p> <p>1 You never need this help                  2 You need this help once in a while                  3 You sometimes need this help                  4 You need this help quite often</p>	

<b>FAMILY SUPPORT SCALE</b>	
<p><b>INSTRUCTIONS:</b> “Now we will look at how helpful the people and groups are to you when raising your grandchild who has a disability. So that we can measure how helpful these different people and groups are to you, the pictures vary from “not at all helpful” to “extremely helpful”. If this person or group is not available to you, you can show this option (<i>point to the not available option</i>) and it means that the person or group is not there in your life. This picture means that the person or group is “not at all helpful”, this one means that they are “sometimes helpful” and this one means that they are “generally helpful” and this one means that they are “extremely helpful” to you. We want to look at how helpful these people or groups have been to you since the past six months (<i>show visual timescale on calender</i>) when raising your grandchild with a disability.”</p>	
0	1
Not available	 Not at all helpful
2	3
 Sometimes helpful	 Generally helpful
4	
 Extremely helpful	
1.	<p>Since the past 6 months how helpful has <b>your husband/wife</b> or partner been</p> <p>Score:</p> <p>0 Not available                  1 Not at all helpful                  2 Sometimes helpful                  3 Generally helpful                  4 Extremely helpful</p> 
2.	<p>Since the past 6 months how helpful have your older child(ren) been</p> <p>Score:</p> <p>0 Not available                  1 Not at all helpful                  2 Sometimes helpful                  3 Generally helpful                  4 Extremely helpful</p> 
3.	<p>Since the past 6 months how helpful have your neighbours been</p> <p>Score:</p> <p>0 Not available                  1 Not at all helpful                  2 Sometimes helpful                  3 Generally helpful                  4 Extremely helpful</p> 
4.	<p>Since the past 6 months how helpful have your parents been</p> <p>Score:</p> <p>0 Not available                  1 Not at all helpful                  2 Sometimes helpful                  3 Generally helpful                  4 Extremely helpful</p> 
5.	<p>Since the past 6 months how helpful have your other grandchildren have been</p> <p>Score:</p> <p>0 Not available                  1 Not at all helpful                  2 Sometimes helpful                  3 Generally helpful                  4 Extremely helpful</p> 














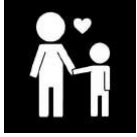

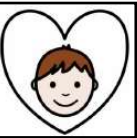



<p>6.</p>	<p>Since the past 6 months how helpful have your relatives been</p> <p><i>Score:</i>                  0 Not available                  1 Not at all helpful                  2 Sometimes helpful                  3 Generally helpful                  4 Extremely helpful</p>	
<p>7.</p>	<p>Since the past 6 months how helpful have your friends been</p> <p><i>Score:</i>                  0 Not available                  1 Not at all helpful                  2 Sometimes helpful                  3 Generally helpful                  4 Extremely helpful</p>	
<p>8.</p>	<p>Since the past 6 months how helpful have the <b>parents of your husband/wife</b> or partner been</p> <p><i>Score:</i>                  0 Not available                  1 Not at all helpful                  2 Sometimes helpful                  3 Generally helpful                  4 Extremely helpful</p>	
<p>9.</p>	<p>Since the past 6 months how helpful have the <b>relatives of your husband/wife</b> or partner been</p> <p><i>Score:</i>                  0 Not available                  1 Not at all helpful                  2 Sometimes helpful                  3 Generally helpful                  4 Extremely helpful</p>	
<p>10.</p>	<p>Since the past 6 months how helpful have the <b>friends of your husband/wife</b> or partner been</p> <p><i>Score:</i>                  0 Not available                  1 Not at all helpful                  2 Sometimes helpful                  3 Generally helpful                  4 Extremely helpful</p>	
<p>11.</p>	<p>Since the past 6 months how helpful has your nanny been</p> <p><i>Score:</i>                  0 Not available                  1 Not at all helpful                  2 Sometimes helpful                  3 Generally helpful                  4 Extremely helpful</p>	
<p>12.</p>	<p>Since the past 6 months how helpful has your employer been</p> <p><i>Score:</i>                  0 Not available                  1 Not at all helpful                  2 Sometimes helpful                  3 Generally helpful                  4 Extremely helpful</p>	








<p>13.</p>	<p>Since the past 6 months how helpful have other grandparents raising their grandchild with a disability been</p> <p><i>Score:</i>                  0 Not available                  1 Not at all helpful                  2 Sometimes helpful                  3 Generally helpful                  4 Extremely helpful</p>	
<p>14.</p>	<p>Since the past 6 months how helpful have other grandparents been</p> <p><i>Score:</i>                  0 Not available                  1 Not at all helpful                  2 Sometimes helpful                  3 Generally helpful                  4 Extremely helpful</p>	
<p>15.</p>	<p>Since the past 6 months how helpful have members of grandparent caregivers support group been</p> <p><i>Score:</i>                  0 Not available                  1 Not at all helpful                  2 Sometimes helpful                  3 Generally helpful                  4 Extremely helpful</p>	
<p>16.</p>	<p>Since the past 6 months how helpful have your co-workers been</p> <p><i>Score:</i>                  0 Not available                  1 Not at all helpful                  2 Sometimes helpful                  3 Generally helpful                  4 Extremely helpful</p>	
<p>17.</p>	<p>Since the past 6 months how helpful have members of your social groups/clubs been</p> <p><i>Score:</i>                  0 Not available                  1 Not at all helpful                  2 Sometimes helpful                  3 Generally helpful                  4 Extremely helpful</p>	
<p>18.</p>	<p>Since the past 6 months how helpful have your fellow religious group members or spiritual leaders been</p> <p><i>Score:</i>                  0 Not available                  1 Not at all helpful                  2 Sometimes helpful                  3 Generally helpful                  4 Extremely helpful</p>	
<p>19.</p>	<p>Since the past 6 months how helpful has your family doctor or the doctor of your grandchild with a disability been</p> <p><i>Score:</i>                  0 Not available                  1 Not at all helpful                  2 Sometimes helpful                  3 Generally helpful                  4 Extremely helpful</p>	


<p>20.</p>	<p>Since the past 6 months how helpful has your grandchild with a disability's care centres/crèche been</p> <p><i>Score:</i>            0 Not available            1 Not at all helpful            2 Sometimes helpful            3 Generally helpful            4 Extremely helpful</p>	
<p>21.</p>	<p>Since the past 6 months how helpful have professional helpers (e.g. social worker, community rehab worker, therapists) been</p> <p><i>Score:</i>            0 Not available            1 Not at all helpful            2 Sometimes helpful            3 Generally helpful            4 Extremely helpful</p>	
<p>22.</p>	<p>Since the past 6 months how helpful have professional services (nurses, social services, mental health etc.) been</p> <p><i>Score:</i>            0 Not available            1 Not at all helpful            2 Sometimes helpful            3 Generally helpful            4 Extremely helpful</p>	
<p>23.</p>	<p>Who are the other people or groups who have been helpful for the past 6 months?</p> <p><i>Write on score sheet:</i> _____</p>	

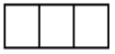








## Appendix I2: Interviewer's Side of Booklet for Each Measure (IsiXhosa)

<b>PARENTAL STRESS SCALE</b>				
<p><b>INSTRUCTIONS:</b> “Siza kuthi sikhangele iimvakalelo zakho malunga nokuba ngumnakekeli sijonge uxinizelelo othi ujongane nalo kwakunye nolwazi lwako gabalala. Kula mabakala khawucingisise ubudlelane onabo nomzukulwana wakho onokhubazeko. Ngokwenza oku sakuti sibone indlela nolwazi gabalala noxinizelelo othi uhlangane nalo ekukhuliseni umzukulwana wako, siza kuthi sijonge ukuba sivumelana okanye asivumelani kangaka kwimibuzo esiza kuthi sikufundele yona. Lo mfanekiso ubonakalisa ukuba kungakanani na ukuvumelana kwako, okuthetha ukuba uyavuma na okanye awuvumelani kwaphela.”</p>				
1  Andivumi konke konke	2  Andivumi	3  Andinasigqibo	4  Ndiyavuma	5  Ndiyavuma kakhulu
1.	<p>Wonwabile kwindima yakho njengomzali nomnakekeli womzukulwana wakho okhubazekileyo</p> <p><i>Score:</i></p> <p>1 Andivumi konke konke 2 Andivumi 3 Andinasigqibo 4 Ndiyavuma 5 Ndiyavuma kakhulu</p>			
2.	<p>Ungenza konke onako ngomzukulwana wakho okhubazekileyo</p> <p><i>Score:</i></p> <p>1 Andivumi konke konke 2 Andivumi 3 Andinasigqibo 4 Ndiyavuma 5 Ndiyavuma kakhulu</p>			
3.	<p>Ukunakekela umzukulwana okhubazekileyo kuthatha ixesha elinzi namandla ngaphezulu kokuba unako</p> <p><i>Score:</i></p> <p>1 Andivumi konke konke 2 Andivumi 3 Andinasigqibo 4 Ndiyavuma 5 Ndiyavuma kakhulu</p>			
4.	<p>Ukukhulisa umzukulwana okhubazekileyo kuthetha ukuba unolawulo oluncinci ngobomi bakho</p> <p><i>Score:</i></p> <p>1 Andivumi konke konke 2 Andivumi 3 Andinasigqibo 4 Ndiyavuma 5 Ndiyavuma kakhulu</p>			
5.	<p>Ngamaxesha ubanexhala lokuba ingaba wenza okwaneleyo kumzukulwana wakho okhubazekileyo</p> <p><i>Score:</i></p> <p>1 Andivumi konke konke 2 Andivumi 3 Andinasigqibo 4 Ndiyavuma 5 Ndiyavuma kakhulu</p>			


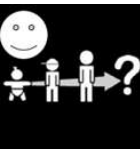





6.	<p>Indlela aziphatha ngayo umzukulwana wakho okhubazekileyo amaxesha amaninzi yenza uxinzelelo</p> <p>Score:</p> <p>1 Andivumi konke konke 2 Andivumi 3 Andinasigqibo 4 Ndiyavuma 5 Ndiyavuma kakhulu</p>	
7.	<p>Uziva usondele kumzukulwana wakho okhubazekileyo</p> <p>Score:</p> <p>1 Andivumi konke konke 2 Andivumi 3 Andinasigqibo 4 Ndiyavuma 5 Ndiyavuma kakhulu</p>	
8.	<p>Uyakonwabela ukuchitha ixesha nomzukulwana wakho okhubazekileyo</p> <p>Score:</p> <p>1 Andivumi konke konke 2 Andivumi 3 Andinasigqibo 4 Ndiyavuma 5 Ndiyavuma kakhulu</p>	
9.	<p>Umzukulwana wakho okhubazekileyo ungumthobo obabulekilyo wothando kuwe</p> <p>Score:</p> <p>1 Andivumi konke konke 2 Andivumi 3 Andinasigqibo 4 Ndiyavuma 5 Ndiyavuma kakhulu</p>	
10.	<p>Ukukhulisa umzukulwana wakho okhubazekileyo kunika isiqinisekiso nombono omhle ngekamva</p> <p>Score:</p> <p>1 Andivumi konke konke 2 Andivumi 3 Andinasigqibo 4 Ndiyavuma 5 Ndiyavuma kakhulu</p>	
11.	<p>Ewona mthombo woxinzelelo ebomini bakho ngumzukulwana wakho okhubazekileyo</p> <p>Score:</p> <p>1 Andivumi konke konke 2 Andivumi 3 Andinasigqibo 4 Ndiyavuma 5 Ndiyavuma kakhulu</p>	
12.	<p>Ukukhulisa umzukulwana wakho okhubazekileyo kukushiya unexeshana lentshukumo ebomini bakho</p> <p>Score:</p> <p>1 Andivumi konke konke 2 Andivumi 3 Andinasigqibo 4 Ndiyavuma 5 Ndiyavuma kakhulu</p>	





<p>13.</p>	<p>Ukukhulisa umzukulwana okhubazekileyo kungumthwalo kuwe ngokwasezimalini  <i>Score:</i>                      1 Andivumi konke konke                      2 Andivumi                      3 Andinasigqibo                      4 Ndiyavuma                      5 Ndiyavuma kakhulu</p>	
<p>14.</p>	<p>Kunzima ukulinganisa nokwenza lonke uxanduva lwakho ngenxa yomzukulwana wakho okhubazekileyo  <i>Score:</i>                      1 Andivumi konke konke                      2 Andivumi                      3 Andinasigqibo                      4 Ndiyavuma                      5 Ndiyavuma kakhulu</p>	
<p>15.</p>	<p>Indlela aziphatha ngayo umzukulwana wakho okhubazekileyo amaxesha amaninzi yenza iintloni.  <i>Score:</i>                      1 Andivumi konke konke                      2 Andivumi                      3 Andinasigqibo                      4 Ndiyavuma                      5 Ndiyavuma kakhulu</p>	
<p>16.</p>	<p>Ukuba bekufuneka uphinde wenze oku ukwenzile ngomzukulwana wakho okhubazekileyo ubunokhetha ukungamkhulisi na umzukulwana wakho  <i>Score:</i>                      1 Andivumi konke konke                      2 Andivumi                      3 Andinasigqibo                      4 Ndiyavuma                      5 Ndiyavuma kakhulu</p>	
<p>17.</p>	<p>Uziva ugubungekile luxanduva loba ngumzali womzukulwana okhubazekileyo  <i>Score:</i>                      1 Andivumi konke konke                      2 Andivumi                      3 Andinasigqibo                      4 Ndiyavuma                      5 Ndiyavuma kakhulu</p>	
<p>18.</p>	<p>Ukukhulisa umzukulwana okhubazekileyo kuthetha ukuba abathuba akho ambalwa  <i>Score:</i>                      1 Andivumi konke konke                      2 Andivumi                      3 Andinasigqibo                      4 Ndiyavuma                      5 Ndiyavuma kakhulu</p>	
<p>19.</p>	<p>Uyaneliseka njengomakhulu  <i>Score:</i>                      1 Andivumi konke konke                      2 Andivumi                      3 Andinasigqibo                      4 Ndiyavuma                      5 Ndiyavuma kakhulu</p>	









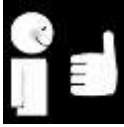

20.	<p>Ufumanisa kukonwabisa na ukuba nomzukulwana wakho onokhubazeko.</p> <p><i>Score:</i></p> <p>1 Andivumi konke konke 2 Andivumi 3 Andinasigqibo 4 Ndiyavuma 5 Ndiyavuma kakhulu</p>	
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<b>PERSONAL WELL-BEING INDEX</b>			
<p><b>INSTRUCTIONS:</b> “Ngokunje siza kuthi sijonge kuwe sizame nokuthi sibale iziganeko ezimalunga nokudinwa nokukhangela ukuba wonwabile na.Singajonga ngolu hlobo ndiziva ngoluhlobo lonke ixesha. Lo ngumfanekiso othetha ukuba awukazange wanemvakalelo ezi lo hlobo okanye abe khona amaxesha apo unemvakalelo ngolu hlobo kwaye yenzeka ngaxesha onke. Cinga ukuba ukhe wanemvakalelo ezi lolu hlobo ekuqalekeni kwenyanga/okanye kwiiveki ezimbini ukhulisa umzukulwana wakho onokhubazeko”</p>			
<p>1</p>  <p>Andizange ndanemvakalelo ezinje</p>	<p>2</p>  <p>Ukhe ubeneemvakalelo ezinje emva kwexesha elide</p>	<p>3</p>  <p>Ukhe ubenemvakalelo ezinje ngamanye amaxesha</p>	<p>4</p>  <p>Ukhe ubenezi mvakalelo ngamanye amaxesha</p>
<p>1.</p>	<p>Ukususela ekuqalekeni kwenyanga/okanye kwiiveki ezimbini ukhe waziva ngathi ubomi bakho buhamba nje kakuhle</p> <p><i>Score:</i></p> <p>1 Andizange ndanemvakalelo ezinje                  2 Ukhe ubeneemvakalelo ezinje emva kwexesha elide                  3 Ukhe ubenemvakalelo ezinje ngamanye amaxesha                  4 Ukhe ubenezi mvakalelo ngamanye amaxesha</p> 		
<p>2.</p>	<p>Ukusukela ekuqalekeni kwenyanga/okanye kwiiveki ezimbini kukangakanani usiva ngathi ubambekile kuxanduva lokunakekela umzukulwana wakho onokhubazeko</p> <p><i>Score:</i></p> <p>1 Andizange ndanemvakalelo ezinje                  2 Ukhe ubeneemvakalelo ezinje emva kwexesha elide                  3 Ukhe ubenemvakalelo ezinje ngamanye amaxesha                  4 Ukhe ubenezi mvakalelo ngamanye amaxesha</p> 		
<p>3.</p>	<p>Ukusukela ekuqalekeni kwenyanga /okanye kwiiveki ezimbini ingaba ufumanise kulula namandla okunakekela umzukulwana wakho onokhubazeko</p> <p><i>Score:</i></p> <p>1 Andizange ndanemvakalelo ezinje                  2 Ukhe ubeneemvakalelo ezinje emva kwexesha elide                  3 Ukhe ubenemvakalelo ezinje ngamanye amaxesha                  4 Ukhe ubenezi mvakalelo ngamanye amaxesha</p> 		
<p>4.</p>	<p>Ukusukela ekuqalekeni kwenyanga/okanye iiveki ezimbini ezidlulileyo ingaba ukhe wangaziva mnandi okanye ungaphilanga</p> <p><i>Score:</i></p> <p>1 Andizange ndanemvakalelo ezinje                  2 Ukhe ubeneemvakalelo ezinje emva kwexesha elide                  3 Ukhe ubenemvakalelo ezinje ngamanye amaxesha                  4 Ukhe ubenezi mvakalelo ngamanye amaxesha</p> 		
<p>5.</p>	<p>Ukusukela ekuqaleni kwenyanga/okanye iiveki ezimbini ezidlulileyominga ukhe waziva kungelula okanye unoloyiko ongalwaziyo ukuba lolwanton na</p> <p><i>Score:</i></p> <p>1 Andizange ndanemvakalelo ezinje                  2 Ukhe ubeneemvakalelo ezinje emva kwexesha elide                  3 Ukhe ubenemvakalelo ezinje ngamanye amaxesha                  4 Ukhe ubenezi mvakalelo ngamanye amaxesha</p> 		



<p>6.</p>	<p>Ukusukela ukuqala kwenyanga/okanye iiveki ezimbini ezidlulileyo ingaba ukhe waziva unokudinwa nokudineka emva kokunakekela umzukulwana wakho onokhubazeko</p> <p><i>Score:</i>          1 Andizange ndanemvakalelo ezinje          2 Ukhe ubeneemvakalelo ezinje emva kwexesha elide          3 Ukhe ubenemvakalelo ezinje ngamanye amaxesha          4 Ukhe ubenezi mvakalelo ngamanye amaxesha</p>	
<p>7.</p>	<p>Ukusukela ukuqala kwenyanga /okanye kwiiveki ezimbini ezidlulileyo ingaba kukangaphi apho uthe waziva wonwabile ngumzukulwana wakho nekamva lakhe</p> <p><i>Score:</i>          1 Andizange ndanemvakalelo ezinje          2 Ukhe ubeneemvakalelo ezinje emva kwexesha elide          3 Ukhe ubenemvakalelo ezinje ngamanye amaxesha          4 Ukhe ubenezi mvakalelo ngamanye amaxesha</p>	
<p>8.</p>	<p>Ukusukela ukuqala kwenyanga okanye iiveki ezimbini ezidlulileyo ngaba ukhe waziva ukudinwa okanye uphantsi na</p> <p><i>Score:</i>          1 Andizange ndanemvakalelo ezinje          2 Ukhe ubeneemvakalelo ezinje emva kwexesha elide          3 Ukhe ubenemvakalelo ezinje ngamanye amaxesha          4 Ukhe ubenezi mvakalelo ngamanye amaxesha</p>	
<p>9.</p>	<p>Ukusukela ekuqaleni kwenyanga okanye kwiiveki ezimbini ezidlulileyo ingaba ukhe weva ukuba iimfuno zomzukulwana wakho onokhubazeko azifikeleli esiphelweni na</p> <p><i>Score:</i>          1 Andizange ndanemvakalelo ezinje          2 Ukhe ubeneemvakalelo ezinje emva kwexesha elide          3 Ukhe ubenemvakalelo ezinje ngamanye amaxesha          4 Ukhe ubenezi mvakalelo ngamanye amaxesha</p>	
<p>10.</p>	<p>Ukusukela ukuqala kwenyanga okanye iiveki ezimbini ezidlulileyo ukhe wazifumanisa unamandla awaneleyo na ukwenza izinto ezininzi ezinje ngomsebenzi wasekhaya</p> <p><i>Score:</i>          1 Andizange ndanemvakalelo ezinje          2 Ukhe ubeneemvakalelo ezinje emva kwexesha elide          3 Ukhe ubenemvakalelo ezinje ngamanye amaxesha          4 Ukhe ubenezi mvakalelo ngamanye amaxesha</p>	
<p>11.</p>	<p>Ukusukela ekuqaleni kwenyanga okanye kwiiveki ezimbini ezidlulileyo ingaba ukhe waziva unompya ophantsi kwakunye noxinizelelo olukhulu lwengqondo</p> <p><i>Score:</i>          1 Andizange ndanemvakalelo ezinje          2 Ukhe ubeneemvakalelo ezinje emva kwexesha elide          3 Ukhe ubenemvakalelo ezinje ngamanye amaxesha          4 Ukhe ubenezi mvakalelo ngamanye amaxesha</p>	
<p>12.</p>	<p>Ukusukela ekuqaleni kwenyanga okanye kwiiveki ezimbini ezidlulileyo ingaba ukhe wanamaxesha okuziva unamandla amakhulu okunakekela umzukulwana wakho onokhubazeko</p> <p><i>Score:</i>          1 Andizange ndanemvakalelo ezinje          2 Ukhe ubeneemvakalelo ezinje emva kwexesha elide          3 Ukhe ubenemvakalelo ezinje ngamanye amaxesha          4 Ukhe ubenezi mvakalelo ngamanye amaxesha</p>	

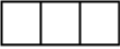








13.	<p>Ukusukela ekuqaleni kwenyanga okanye kwiiveki ezimbini ezidlulilyo ingaba uye wafumana ukuzonwabela izinto ezithile ezenziwa ngumzukulwana wakho onokhubazeko</p> <p><i>Score:</i></p> <p>1 Andizange ndanemvakalelo ezinje  2 Ukhe ubeneemvakalelo ezinje emva kwexesha elide  3 Ukhe ubenemvakalelo ezinje ngamanye amaxesha  4 Ukhe ubenezi mvakalelo ngamanye amaxesha</p>	
14.	<p>Ukususela ekuqalekeni kwenyanga okanye kwiiveki ezimbini ezidlulileyo ingaba ukhe waziva unohulumanco olukhulu</p> <p><i>Score:</i></p> <p>1 Andizange ndanemvakalelo ezinje  2 Ukhe ubeneemvakalelo ezinje emva kwexesha elide  3 Ukhe ubenemvakalelo ezinje ngamanye amaxesha  4 Ukhe ubenezi mvakalelo ngamanye amaxesha</p>	
15.	<p>Ukususela ekuqalekeni kwenyanga okanye kwiiveki ezimbini ezidlulileyo ukhe wafumanisa ukuba ukunakekela umzukulwana wakho onokubazeko kukufakela uxinzelelo olukhulu</p> <p><i>Score:</i></p> <p>1 Andizange ndanemvakalelo ezinje  2 Ukhe ubeneemvakalelo ezinje emva kwexesha elide  3 Ukhe ubenemvakalelo ezinje ngamanye amaxesha  4 Ukhe ubenezi mvakalelo ngamanye amaxesha</p>	
16.	<p>Ukususela ekuqalekeni kwenyanga okanye kwiiveki ezimbini ezidlulileyo ingaba ukhe waziva usemandleni kakhulu</p> <p><i>Score:</i></p> <p>1 Andizange ndanemvakalelo ezinje  2 Ukhe ubeneemvakalelo ezinje emva kwexesha elide  3 Ukhe ubenemvakalelo ezinje ngamanye amaxesha  4 Ukhe ubenezi mvakalelo ngamanye amaxesha</p>	





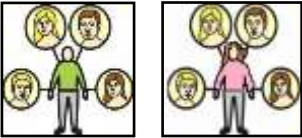
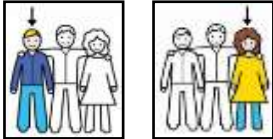
<b>SUPPORT FUNCTIONS SCALE</b>			
<p><b>INSTRUCTIONS:</b> “Ngokunje siza kujonga kwiintlobo ngeentlobo zenkxaso oyifunayo nekufumaniseke ukuba ingaluncedo kakhulu kuwe. Ukuqikelela inkxaso noncedo othe walufumana lukunceda kakhulu apho ke kunokwenzeka ukuba iyakunceda ngamanye amaxa okanye maxa onke. Lo mfanekiso ngowukuba awuzanga waludinga olu ncedo, lo ngowukuba wawukhe uludinge kanye ethubeni, lo umfanekiso ngowokuba ukhe uludinge oluncedo ngamaxa athile kwangokunjalo lo ngowokuba usoloko uludinga olu ncedo.”</p>			
<p>1</p>  <p>Awuzange wakhe walufuna olu uncedo</p>	<p>2</p>  <p>Ukhe ulufune oluncedo ngamaxesha athile</p>	<p>3</p>  <p>Ngamaxesha athile ukhe ulufune olu ncedo</p>	<p>4</p>  <p>Ulufuna olu ncedo ngamaxesha onke</p>
1.	<p><b>Kukangapi uziva ufuna ukuthetha nomntu malunga nezinto ezikubangela inkxalabo</b>  <i>Score:</i>                      1 Awuzange wakhe walufuna olu uncedo                      2 Ukhe ulufune oluncedo ngamaxesha athile                      3 Ngamaxesha athile ukhe ulufune olu ncedo                      4 Ulufuna olu ncedo ngamaxesha onke</p>		
2.	<p><b>Kukangaphi uziva ufuna umntu wokukuncedisa ekunakekeleni umzukulwana wakho onokhubazeko</b>  <i>Score:</i>                      1 Awuzange wakhe walufuna olu uncedo                      2 Ukhe ulufune oluncedo ngamaxesha athile                      3 Ngamaxesha athile ukhe ulufune olu ncedo                      4 Ulufuna olu ncedo ngamaxesha onke</p>		
3.	<p><b>Kukanagaphi uziva ufuna umntu onokuthetha naye xa unemibuzo malunga nokukhulisa umzukuulwana wakho onokhubazeko</b>  <i>Score:</i>                      1 Awuzange wakhe walufuna olu uncedo                      2 Ukhe ulufune oluncedo ngamaxesha athile                      3 Ngamaxesha athile ukhe ulufune olu ncedo                      4 Ulufuna olu ncedo ngamaxesha onke</p>		
4.	<p><b>Kukangaphi uziva ufuna umntu onokuthi akuboleke imali xa uyifuna</b>  <i>Score:</i>                      1 Awuzange wakhe walufuna olu uncedo                      2 Ukhe ulufune oluncedo ngamaxesha athile                      3 Ngamaxesha athile ukhe ulufune olu ncedo                      4 Ulufuna olu ncedo ngamaxesha onke</p>		
5.	<p><b>Kukangaphi uziva ufuna umntu onokuthi akukhuthaze akuvuselela xa izinto zinobunzima</b>  <i>Score:</i>                      1 Awuzange wakhe walufuna olu uncedo                      2 Ukhe ulufune oluncedo ngamaxesha athile                      3 Ngamaxesha athile ukhe ulufune olu ncedo                      4 Ulufuna olu ncedo ngamaxesha onke</p>		
6.	<p><b>Kukangaphi uziva ufuna umntu onokwamkela umzukulwana wakho onokhubazeko nangeendlela enza ngazo izinto</b>  <i>Score:</i>                      1 Awuzange wakhe walufuna olu uncedo                      2 Ukhe ulufune oluncedo ngamaxesha athile                      3 Ngamaxesha athile ukhe ulufune olu ncedo                      4 Ulufuna olu ncedo ngamaxesha onke</p>		


7.	<p><b>Kukangaphi uziva ufuna umntu wokuncedisa kwimisebenzi yekhaya</b>  <i>Score:</i>                      1 Awuzange wakhe walufuna olu uncedo                      2 Ukhe ulufune oluncedo ngamaxesha athile                      3 Ngamaxesha athile ukhe ulufune olu ncedo                      4 Ulufuna olu ncedo ngamaxesha onke</p>	
8.	<p><b>Kukangaphi uziva ufuna umntu onokthi uphumle kwaye uhleke naye</b>  <i>Score:</i>                      1 Awuzange wakhe walufuna olu uncedo                      2 Ukhe ulufune oluncedo ngamaxesha athile                      3 Ngamaxesha athile ukhe ulufune olu ncedo                      4 Ulufuna olu ncedo ngamaxesha onke</p>	
9.	<p><b>Kukangaphi uziva ufuna umntu onokuthi enze izinto kunye nomzukulwana wakho onokhubazeko</b>  <i>Score:</i>                      1 Awuzange wakhe walufuna olu uncedo                      2 Ukhe ulufune oluncedo ngamaxesha athile                      3 Ngamaxesha athile ukhe ulufune olu ncedo                      4 Ulufuna olu ncedo ngamaxesha onke</p>	
10.	<p><b>Kukangaphi uziva ufuna umntu onokukunceda ngomzukulwana wakho onokhubazeko okanye wena ngeenkonzo zothutho</b>  <i>Score:</i>                      1 Awuzange wakhe walufuna olu uncedo                      2 Ukhe ulufune oluncedo ngamaxesha athile                      3 Ngamaxesha athile ukhe ulufune olu ncedo                      4 Ulufuna olu ncedo ngamaxesha onke</p>	
11.	<p><b>Kukanganani uziva ufuna umntu onokuthi alandelele ngeenkonzo zemali SASSA (umzekelo inkxaso zemali) isibhedlele iinkonzo zempilo (umzekelo unyango, ukubonana nogqirha) xa wena ungenako</b>  <i>Score:</i>                      1 Awuzange wakhe walufuna olu uncedo                      2 Ukhe ulufune oluncedo ngamaxesha athile                      3 Ngamaxesha athile ukhe ulufune olu ncedo                      4 Ulufuna olu ncedo ngamaxesha onke</p>	
12.	<p><b>Kukanganani uziva ufuna umntu onokuthi akuxelele ngeenkonzo malunga nomzukulwana wakho onokhubazeko</b>  <i>Score:</i>                      1 Awuzange wakhe walufuna olu uncedo                      2 Ukhe ulufune oluncedo ngamaxesha athile                      3 Ngamaxesha athile ukhe ulufune olu ncedo                      4 Ulufuna olu ncedo ngamaxesha onke</p>	


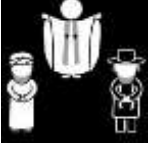

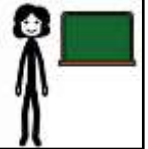


### FAMILY SUPPORT SCALE

**INSTRUCTIONS:** “Ngoku siza kukhe sijonge ukuba abantu namaqela baluncedo kangakanani na kuwe ekhukhuliseni umzukulwana wakho onokhubazeko. Ngokwenza oku singathi sibenokuqikelela ukuba abantu ngokohlukana kwabo kwakunye nemifanekiso eyahlukeneyo iyakunceda na ngokwaneleyo okanye ziluncedo kakhulu. Ukuba lo mntu okanye eli qela liyafumaneka kuwe ungakhetha kolu luhlu. Lo mfanekiso ithetha ukuba lomntu okanye eli qela liyabandakanyek. A kubomi bakho, lo mfanekiso ubonakalisa ukuba lo mntu okanye eli qela ayiloncedo kuwe konke konke, lo uthetha ukuthi ngamanye amaxesha babaluncedo kananjalo lo ubonakilisa ukuba baluncedo bekwaluncedo olukhulu kananjalo kuwe. Sifuna ukujonga ukuba ukuba aba bantu nala maqela baluncedo kangakanani na kuwe ukusukela kwiinyanga ezintandathu ezidluliyi (*show visual timescale on calender*) xa ukhulisa umzukulwana wakho onokubazeko.”

0	1	2	3	4
Alukho	 Alukho uncedo konke konke	 Uluncedo ngamanye amaxesha	 Uluncedo	 Uluncedo kahulu
1.	<p>Ukususela kwinyanga ezintandathu ezidlulileyo ingaba luncedo olungakanani ubulufumana kumyeni okanye kuknosikazi okanye umlingano</p> <p><i>Score:</i>            0 Alukho            1 Alukho uncedo konke konke            2 Uluncedo ngamanye amaxesha            3 Uluncedo            4 Uluncedo kahulu</p>			
	 			
2.	<p>Ukususela kwinyanga ezintandathu ezidlulileyo ingaba belungakanani na uncedo obulufumana kubantwana bakho abadala</p> <p><i>Score:</i>            0 Alukho            1 Alukho uncedo konke konke            2 Uluncedo ngamanye amaxesha            3 Uluncedo            4 Uluncedo kahulu</p>			
				
3.	<p>Ukususela kwiinyanga ezintandathu ezidlulileyo abamelwana bakho bebekuncedisa kangakanani na</p> <p><i>Score:</i>            0 Alukho            1 Alukho uncedo konke konke            2 Uluncedo ngamanye amaxesha            3 Uluncedo            4 Uluncedo kahulu</p>			
				
4.	<p>Ukususela kwiinyanga ezintandathu ezidlulileyo bebekuncedisa kangakanani na abazali bakho</p> <p><i>Score:</i>            0 Alukho            1 Alukho uncedo konke konke            2 Uluncedo ngamanye amaxesha            3 Uluncedo            4 Uluncedo kahulu</p>			
				











<p>5.</p>	<p>Ukususela kwiinyanga ezintandathu ezidlulileyo ingaba belulungakanani uncedo ubulifumana kubazukulwana bakho</p> <p><i>Score:</i>                  0 Alukho                  1 Alukho uncedo konke konke                  2 Uluncedo ngamanye amaxesha                  3 Uluncedo                  4 Uluncedo kahulu</p>	
<p>6.</p>	<p>Ukususela kwiinyanga ezintandathu ezidlulileyo ingaba beziluncedo olungakanani na izizalwana zakho</p> <p><i>Score:</i>                  0 Alukho                  1 Alukho uncedo konke konke                  2 Uluncedo ngamanye amaxesha                  3 Uluncedo                  4 Uluncedo kahulu</p>	
<p>7.</p>	<p>Ukususela kwiinyanga ezintandathu ezidlulileyo ingaba beziluncedo olungakanani na izihlobo zakho</p> <p><i>Score:</i>                  0 Alukho                  1 Alukho uncedo konke konke                  2 Uluncedo ngamanye amaxesha                  3 Uluncedo                  4 Uluncedo kahulu</p>	
<p>8.</p>	<p>Ukusesela kwiintanga ezintandathu ezidlulileyo ingaba ebeluncedo olungakanani na umyeni wakho/ okanye unkosikazi okanye umlingane wakho</p> <p><i>Score:</i>                  0 Alukho                  1 Alukho uncedo konke konke                  2 Uluncedo ngamanye amaxesha                  3 Uluncedo                  4 Uluncedo kahulu</p>	
<p>9.</p>	<p>Ukususela kwiinyanga ezintandathu ezidlulileyo ingaba beziluncedo kangakanani na izihlobo zakulomyeni wakho/ okanye unkosikazi wakho okanye umlingane wakho</p> <p><i>Score:</i>                  0 Alukho                  1 Alukho uncedo konke konke                  2 Uluncedo ngamanye amaxesha                  3 Uluncedo                  4 Uluncedo kahulu</p>	
<p>10.</p>	<p>Ukususela kwiinyanga ezintandathu ezidlulileyo ingaba beziluncedo kangakanani na izihlobo zomyeni wakho</p> <p><i>Score:</i>                  0 Alukho                  1 Alukho uncedo konke konke                  2 Uluncedo ngamanye amaxesha                  3 Uluncedo                  4 Uluncedo kahulu</p>	


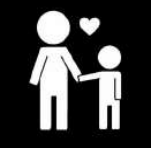

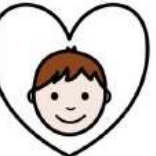
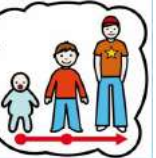
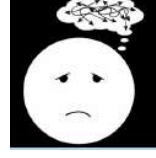

<p>11.</p>	<p>Ukususela kwinyanga ezintandathu ezidlulileyo ebeluncedo olungakanani na umnakekeli wakho  <i>Score:</i>                  0 Alukho                  1 Alukho uncedo konke konke                  2 Uluncedo ngamanye amaxesha                  3 Uluncedo                  4 Uluncedo kahulu</p>	
<p>12.</p>	<p>Ukususela kwiinyanga ezintandathu ezidlulileyo ebeluncedo kangakanani na umqeshi wakho  <i>Score:</i>                  0 Alukho                  1 Alukho uncedo konke konke                  2 Uluncedo ngamanye amaxesha                  3 Uluncedo                  4 Uluncedo kahulu</p>	
<p>13.</p>	<p>Ukususela kwiinyanga ezintandathu ezidlulileyo ingaba beziluncedo olungakanani na abanye oogogo ekukhuliseni abantwana babo abanokhubazeko  <i>Score:</i>                  0 Alukho                  1 Alukho uncedo konke konke                  2 Uluncedo ngamanye amaxesha                  3 Uluncedo                  4 Uluncedo kahulu</p>	
<p>14.</p>	<p>Ukususela kwiinyanga ezintandathu ezidlulileyo igaba bebeluncedo olunjani abanye oomhakhulu nootatomkhulu  <i>Score:</i>                  0 Alukho                  1 Alukho uncedo konke konke                  2 Uluncedo ngamanye amaxesha                  3 Uluncedo                  4 Uluncedo kahulu</p>	
<p>15.</p>	<p>Ukususela kwiinyanga ezintandathu ezidlulileyo bebeluncedo olungakanani na abanye oomhakhulu nootatomkhulu kwiindibano zenkxaso  <i>Score:</i>                  0 Alukho                  1 Alukho uncedo konke konke                  2 Uluncedo ngamanye amaxesha                  3 Uluncedo                  4 Uluncedo kahulu</p>	
<p>16.</p>	<p>Ukususela kwiinyanga ezintandathu ezidlulileyo belungakanani na uncedo kubasenzi osebenza nabo  <i>Score:</i>                  0 Alukho                  1 Alukho uncedo konke konke                  2 Uluncedo ngamanye amaxesha                  3 Uluncedo                  4 Uluncedo kahulu</p>	




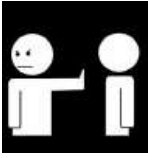


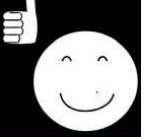
<p>17.</p>	<p>Ukususela kwiinyanga ezintandathu ezidlulileyo ebeluncedo olungakanani na amanye amalungu eendibano zasekuhlaleni</p> <p><i>Score:</i>                  0 Alukho                  1 Alukho uncedo konke konke                  2 Uluncedo ngamanye amaxesha                  3 Uluncedo                  4 Uluncedo kahulu</p>	
<p>18.</p>	<p>Ukususela kwiinyanga ezintandathu ezidlulileyo zibe ziluncedo kangakanani na amaqela eenkonzo okanye aiinkokheli ngokwasemoyeni</p> <p><i>Score:</i>                  0 Alukho                  1 Alukho uncedo konke konke                  2 Uluncedo ngamanye amaxesha                  3 Uluncedo                  4 Uluncedo kahulu</p>	
<p>19.</p>	<p>Ukususela kwiinyanga ezintandathu ezidlulileyo ebeluncedo olunjani ugqirha wakho wekhaya okanye ugqirha womzukulwana wakho onokhubazeko</p> <p><i>Score:</i>                  0 Alukho                  1 Alukho uncedo konke konke                  2 Uluncedo ngamanye amaxesha                  3 Uluncedo                  4 Uluncedo kahulu</p>	
<p>20.</p>	<p>Ukususela kwiinyanga ezintandathu ezidlulileyo ebeluncedo olunjani amaziko okunakekela umzukulwana wakho onokhubazeko</p> <p><i>Score:</i>                  0 Alukho                  1 Alukho uncedo konke konke                  2 Uluncedo ngamanye amaxesha                  3 Uluncedo                  4 Uluncedo kahulu</p>	
<p>21.</p>	<p>Ukususela kwiinyanga ezintandathu ezidlulileyo bebeluncedo olungakanani na onoontlalontle, abancedisi basekuhlaleni kwakunye nabanyangi</p> <p><i>Score:</i>                  0 Alukho                  1 Alukho uncedo konke konke                  2 Uluncedo ngamanye amaxesha                  3 Uluncedo                  4 Uluncedo kahulu</p>	
<p>22.</p>	<p>Ukususela kwiinyanga ezintandathu ezidlulileyo bebeluncedo olunjani kumaziko ezakhono abongikazi, onoontlalontle kwakunye nabanyangi bezengqondo</p> <p><i>Score:</i>                  0 Alukho                  1 Alukho uncedo konke konke                  2 Uluncedo ngamanye amaxesha                  3 Uluncedo                  4 Uluncedo kahulu</p>	
<p>23.</p>	<p>Ingaba ngoobani abanye abantu okanye amanye amaqela ebeluncedo kwiinyanga ezintandathu ezidlulileyo?</p>	













### Appendix I3: Interviewer's Side of Booklet for Each Measure (Afrikaans)








PARENTAL STRESS SCALE				
<p><b>AFRIKAANS:</b> “Ons sal nou kyk na hoe u/jy daarvoor voel om ’n versorger te wees en ons gaan meet hoeveel stres u/jy as versorger ervaar. Vir elkeen van die volgende sinne, dink oor u/jou verhouding met u/jou gestremde kleinkind. Om te meet hoeveel stres u/jy ervaar in die grootmaak van u/jou kleinkind, sal ons die sinne vir u/jou lees en luister tot watter mate u/jy daarmee saamstem of nie. Hierdie prentjie beteken u/jy stem ten sterkste saam, hierdie een beteken u/jy stem saam, hierdie een beteken u/jy stem nie saam nie en hierdie een beteken u/jy stem ten sterkste nie saam nie”.</p>				
1	2	3	4	5
				
Stem ten sterkste nie saam nie	Stem nie saam nie	Onseker	Stem saam	Stem ten sterkste saam
1.	U/Jy is gelukkig in u/jou rol as ’n versorger van u/jou gestremde kleinkind			
	<p>Score:</p> <p>1 Stem ten sterkste nie saam nie</p> <p>2 Stem nie saam nie</p> <p>3 Onseker</p> <p>4 Stem saam</p> <p>5 Stem ten sterkste saam</p>			
2.	U/jy sal doen wat u/jy ook al kan doen vir u/jou gestremde kleinkind			
	<p>Score:</p> <p>1 Stem ten sterkste nie saam nie</p> <p>2 Stem nie saam nie</p> <p>3 Onseker</p> <p>4 Stem saam</p> <p>5 Stem ten sterkste saam</p>			
3.	Die versorging van u/jou gestremde kleinkind neem soms meer tyd en energie as wat u/jy het om te gee			
	<p>Score:</p> <p>1 Stem ten sterkste nie saam nie</p> <p>2 Stem nie saam nie</p> <p>3 Onseker</p> <p>4 Stem saam</p> <p>5 Stem ten sterkste saam</p>			
4.	Die grootmaak van u/jou gestremde kleinkind het beteken dat u/jy te min beheer oor u/jou lewe het			
	<p>Score:</p> <p>1 Stem ten sterkste nie saam nie</p> <p>2 Stem nie saam nie</p> <p>3 Onseker</p> <p>4 Stem saam</p> <p>5 Stem ten sterkste saam</p>			
5.	U/Jy wonder soms of u/jy genoeg doen vir u/jou gestremde kleinkind			
	<p>Score:</p> <p>1 Stem ten sterkste nie saam nie</p> <p>2 Stem nie saam nie</p> <p>3 Onseker</p> <p>4 Stem saam</p> <p>5 Stem ten sterkste saam</p>			





6.	<p>Die gedrag van u/jou gestremde kleinkind is dikwels vir u/jou stresvol</p> <p><i>Score:</i></p> <p>1 Stem ten sterkste nie saam nie  2 Stem nie saam nie  3 Onseker  4 Stem saam  5 Stem ten sterkste saam</p>	
7.	<p>U/Jy voel na aan u/jou gestremde kleinkind</p> <p><i>Score:</i></p> <p>1 Stem ten sterkste nie saam nie  2 Stem nie saam nie  3 Onseker  4 Stem saam  5 Stem ten sterkste saam</p>	
8.	<p>U/Jy geniet dit om tyd saam met u/jou gestremde kleinkind deur te bring</p> <p><i>Score:</i></p> <p>1 Stem ten sterkste nie saam nie  2 Stem nie saam nie  3 Onseker  4 Stem saam  5 Stem ten sterkste saam</p>	
9.	<p>U/Jou gestremde kleinkind is 'n belangrike bron van liefde vir u/jou</p> <p><i>Score:</i></p> <p>1 Stem ten sterkste nie saam nie  2 Stem nie saam nie  3 Onseker  4 Stem saam  5 Stem ten sterkste saam</p>	
10.	<p>Die grootmaak van u/jou gestremde kleinkind bied aan u/jou 'n seker en meer positiewe siening van die toekoms</p> <p><i>Score:</i></p> <p>1 Stem ten sterkste nie saam nie  2 Stem nie saam nie  3 Onseker  4 Stem saam  5 Stem ten sterkste saam</p>	
11.	<p>Die grootste bron van stres in u/jou lewe is u/jou gestremde kleinkind</p> <p><i>Score:</i></p> <p>1 Stem ten sterkste nie saam nie  2 Stem nie saam nie  3 Onseker  4 Stem saam  5 Stem ten sterkste saam</p>	
12.	<p>Die grootmaak van u/jou gestremde kleinkind laat min tyd en buigsaamheid in u/jou lewe toe</p> <p><i>Score:</i></p> <p>1 Stem ten sterkste nie saam nie  2 Stem nie saam nie  3 Onseker  4 Stem saam  5 Stem ten sterkste saam</p>	








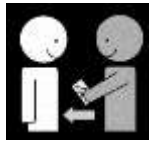
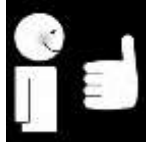

<p>13.</p>	<p>Dit is 'n finansiële las om u/jou gestremde kleinkind groot te maak</p> <p><i>Score:</i></p> <p>1 Stem ten sterkste nie saam nie                  2 Stem nie saam nie                  3 Onseker                  4 Stem saam                  5 Stem ten sterkste saam</p>	
<p>14.</p>	<p>Dit is moeilik om verskillende verantwoordelikhede te balanseer as gevolg van u/jou gestremde kleinkind</p> <p><i>Score:</i></p> <p>1 Stem ten sterkste nie saam nie                  2 Stem nie saam nie                  3 Onseker                  4 Stem saam                  5 Stem ten sterkste saam</p>	
<p>15.</p>	<p>Die gedrag van u/jou gestremde kleinkind is dikwels vir u/jou 'n verleentheid</p> <p><i>Score:</i></p> <p>1 Stem ten sterkste nie saam nie                  2 Stem nie saam nie                  3 Onseker                  4 Stem saam                  5 Stem ten sterkste saam</p>	
<p>16.</p>	<p>As u/jy dit weer moes oordoen, sou u/jy dalk besluit het om nie u/jou gestremde kleinkind groot te maak nie</p> <p><i>Score:</i></p> <p>1 Stem ten sterkste nie saam nie                  2 Stem nie saam nie                  3 Onseker                  4 Stem saam                  5 Stem ten sterkste saam</p>	
<p>17.</p>	<p>U/jy voel oorweldig deur die verantwoordelikheid daarvan om 'n ouer vir u/jou gestremde kleinkind te wees</p> <p><i>Score:</i></p> <p>1 Stem ten sterkste nie saam nie                  2 Stem nie saam nie                  3 Onseker                  4 Stem saam                  5 Stem ten sterkste saam</p>	
<p>18.</p>	<p>Die grootmaak van u/jou gestremde kleinkind het beteken dat u/jy te min keuses in u/jou lewe het</p> <p><i>Score:</i></p> <p>1 Stem ten sterkste nie saam nie                  2 Stem nie saam nie                  3 Onseker                  4 Stem saam                  5 Stem ten sterkste saam</p>	
<p>19.</p>	<p>U/Jy is tevrede as 'n grootouer</p> <p><i>Score:</i></p> <p>1 Stem ten sterkste nie saam nie                  2 Stem nie saam nie                  3 Onseker                  4 Stem saam                  5 Stem ten sterkste saam</p>	

20.	<p>U/Jy geniet u/jou gestremde kleinkind</p> <p><i>Score:</i></p> <p>1 Stem ten sterkste nie saam nie</p> <p>2 Stem nie saam nie</p> <p>3 Onseker</p> <p>4 Stem saam</p> <p>5 Stem ten sterkste saam</p>	
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<b>PERSONAL WELL-BEING INDEX</b>	
<p><b>INSTRUCTIONS:</b> “Ons gaan nou na u/jou welstand kyk en ons sal kyk na hoe u/jy dikwels voel, byvoorbeeld hoe dikwels u/jy moeg voel en hoe dikwels u/jy gelukkig voel. Dit wissel van ‘Ek voel nooit so nie’ tot ‘Ek voel altyd so’. Hierdie prentjie beteken u/jy voel nooit so nie, hierdie een beteken u/jy voel af en toe so, hierdie een beteken u/jy voel soms so en hierdie een beteken u/jy voel dikwels so. Dink oor hoe u/jy gevoel het sedert die begin van die maand/die afgelope twee weke.”</p>	
<p>1</p>  <p>U/jy het nog nooit so gevoel nie</p>	<p>2</p>  <p>U/jy het al af en toe so gevoel</p>
<p>3</p>  <p>U/jy het al soms so gevoel</p>	<p>4</p>  <p>U/jy het al dikwels so gevoel</p>
<p>1.</p>	<p>Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy gevoel dat u/jy 'n baie goeie lewe het</p> <p><i>Score:</i></p> <p>1 U/jy het nog nooit so gevoel nie            2 U/jy het al af en toe so gevoel            3 U/jy het al soms so gevoel            4 U/jy het al dikwels so gevoel</p> 
<p>2.</p>	<p>Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy vasgevang gevoel deur u/jou verantwoordelikhede as 'n versorger</p> <p><i>Score:</i></p> <p>1 U/jy het nog nooit so gevoel nie            2 U/jy het al af en toe so gevoel            3 U/jy het al soms so gevoel            4 U/jy het al dikwels so gevoel</p> 
<p>3.</p>	<p>Sedert die begin van die maand/die afgelope twee weke, hoe dikwels was dit vir u/jou maklik om u/jou gestremde kleinkind fisies te versorg</p> <p><i>Score:</i></p> <p>1 U/jy het nog nooit so gevoel nie            2 U/jy het al af en toe so gevoel            3 U/jy het al soms so gevoel            4 U/jy het al dikwels so gevoel</p> 
<p>4.</p>	<p>Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy nie lekker gevoel nie, of siek gevoel</p> <p><i>Score:</i></p> <p>1 U/jy het nog nooit so gevoel nie            2 U/jy het al af en toe so gevoel            3 U/jy het al soms so gevoel            4 U/jy het al dikwels so gevoel</p> 
<p>5.</p>	<p>Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy ongemaklik of bang gevoel sonder dat u/jy weet hoekom</p> <p><i>Score:</i></p> <p>1 U/jy het nog nooit so gevoel nie            2 U/jy het al af en toe so gevoel            3 U/jy het al soms so gevoel            4 U/jy het al dikwels so gevoel</p> 




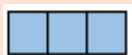





6.	<p>Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy moeg of uitgeput gevoel nadat u/jy u/jou gestremde kleinkind versorg het</p> <p>Score:</p> <p>1 U/jy het nog nooit so gevoel nie</p> <p>2 U/jy het al af en toe so gevoel</p> <p>3 U/jy het al soms so gevoel</p> <p>4 U/jy het al dikwels so gevoel</p>	
7.	<p>Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy gelukkig gevoel oor u/jou gestremde kleinkind se toekoms</p> <p>Score:</p> <p>1 U/jy het nog nooit so gevoel nie</p> <p>2 U/jy het al af en toe so gevoel</p> <p>3 U/jy het al soms so gevoel</p> <p>4 U/jy het al dikwels so gevoel</p>	
8.	<p>Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy moeg of ooreis gevoel</p> <p>Score:</p> <p>1 U/jy het nog nooit so gevoel nie</p> <p>2 U/jy het al af en toe so gevoel</p> <p>3 U/jy het al soms so gevoel</p> <p>4 U/jy het al dikwels so gevoel</p>	
9.	<p>Sedert die begin van die maand/die afgelope twee weke, hoe dikwels is daar vir u/jou geen einde aan die eise wat u/jou gestremde kleinkind aan u/jou stel nie</p> <p>Score:</p> <p>1 U/jy het nog nooit so gevoel nie</p> <p>2 U/jy het al af en toe so gevoel</p> <p>3 U/jy het al soms so gevoel</p> <p>4 U/jy het al dikwels so gevoel</p>	
10.	<p>Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy baie energie gehad om dinge gedoen te kry (bv. huishoudelike take)</p> <p>Score:</p> <p>1 U/jy het nog nooit so gevoel nie</p> <p>2 U/jy het al af en toe so gevoel</p> <p>3 U/jy het al soms so gevoel</p> <p>4 U/jy het al dikwels so gevoel</p>	
11.	<p>Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy terneergedruk of depressief gevoel</p> <p>Score:</p> <p>1 U/jy het nog nooit so gevoel nie</p> <p>2 U/jy het al af en toe so gevoel</p> <p>3 U/jy het al soms so gevoel</p> <p>4 U/jy het al dikwels so gevoel</p>	
12.	<p>Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy baie energie gehad om by te hou by u/jou gestremde kleinkind</p> <p>Score:</p> <p>1 U/jy het nog nooit so gevoel nie</p> <p>2 U/jy het al af en toe so gevoel</p> <p>3 U/jy het al soms so gevoel</p> <p>4 U/jy het al dikwels so gevoel</p>	




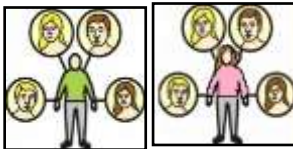
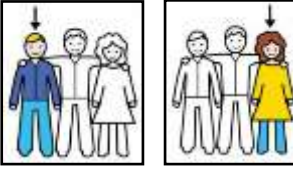

13.	<p>Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy plesier gevind in die dinge wat u/jou gestremde kleinkind doen</p> <p><i>Score:</i></p> <p>1 U/jy het nog nooit so gevoel nie  2 U/jy het al af en toe so gevoel  3 U/jy het al soms so gevoel  4 U/jy het al dikwels so gevoel</p>	
14.	<p>Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy werklik gelukkig gevoel</p> <p><i>Score:</i></p> <p>1 U/jy het nog nooit so gevoel nie  2 U/jy het al af en toe so gevoel  3 U/jy het al soms so gevoel  4 U/jy het al dikwels so gevoel</p>	
15.	<p>Sedert die begin van die maand/die afgelope twee weke, hoe dikwels is dit 'n stremming vir u/jou om u/jou gestremde kleinkind te versorg</p> <p><i>Score:</i></p> <p>1 U/jy het nog nooit so gevoel nie  2 U/jy het al af en toe so gevoel  3 U/jy het al soms so gevoel  4 U/jy het al dikwels so gevoel</p>	
16.	<p>Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy gevoel asof u/jy in 'n goeie fisiese toestand is</p> <p><i>Score:</i></p> <p>1 U/jy het nog nooit so gevoel nie  2 U/jy het al af en toe so gevoel  3 U/jy het al soms so gevoel  4 U/jy het al dikwels so gevoel</p>	







<b>SUPPORT FUNCTIONS SCALE</b>			
<p><b>INSTRUCTIONS:</b> “Ons sal nou kyk na die tipes ondersteuning wat u/jy nodig het en wat vir u/jou waarde het. Om te kan meet watter ondersteuning u/jy nodig het en wat vir u/jou waarde het, sal ons kyk na hoe nodig u/jy hierdie soort hulp het. Dit wissel van ‘nooit’ na ‘dikwels’. Hierdie prentjie is beteken u/jy nooit hierdie hulp nodig het nie, hierdie een beteken u/jy dit af en toe benodig, hierdie prentjie beteken u/jy dit soms benodig, en hierdie een beteken u/jy dit dikwels nodig het.”</p>			
<p><b>1</b></p>  <p>U/jy benodig nooit hulp hiermee nie</p>	<p><b>2</b></p>  <p>U/jy benodig af en toe hulp hiermee</p>	<p><b>3</b></p>  <p>U/jy benodig soms hulp hiermee</p>	<p><b>4</b></p>  <p>U/jy benodig baie dikwels hulp hiermee</p>
<p>1.</p>	<p>Hoe dikwels benodig u/jy iemand waarmee u/jy kan praat oor dinge wat u/jou bekommer</p> <p><i>Score:</i></p> <p>1 Benodig nooit hulp hiermee nie                  2 Benodig af en toe hulp hiermee                  3 Benodig soms hulp hiermee                  4 Benodig dikwels hulp hiermee</p>		
<p>2.</p>	<p>Hoe dikwels benodig u/jy iemand wat u/jou kan help met die versorging van u/jou gestremde kleinkind</p> <p><i>Score:</i></p> <p>1 Benodig nooit hulp hiermee nie                  2 Benodig af en toe hulp hiermee                  3 Benodig soms hulp hiermee                  4 Benodig dikwels hulp hiermee</p>		
<p>3.</p>	<p>Hoe dikwels benodig u/jy iemand waarmee u/jy kan praat wanneer u/jy vrae het oor die grootmaak van u/jou gestremde kleinkind</p> <p><i>Score:</i></p> <p>1 Benodig nooit hulp hiermee nie                  2 Benodig af en toe hulp hiermee                  3 Benodig soms hulp hiermee                  4 Benodig dikwels hulp hiermee</p>		
<p>4.</p>	<p>Hoe dikwels benodig u/jy iemand wat vir u/jou kan geld leen wanneer u/jy dit nodig het</p> <p><i>Score:</i></p> <p>1 Benodig nooit hulp hiermee nie                  2 Benodig af en toe hulp hiermee                  3 Benodig soms hulp hiermee                  4 Benodig dikwels hulp hiermee</p>		
<p>5.</p>	<p>Hoe dikwels benodig u/jy iemand om u/jou moed in te praat of u/jou te help om aan te gaan wanneer dit moeilik is</p> <p><i>Score:</i></p> <p>1 Benodig nooit hulp hiermee nie                  2 Benodig af en toe hulp hiermee                  3 Benodig soms hulp hiermee                  4 Benodig dikwels hulp hiermee</p>		
<p>6.</p>	<p>Hoe dikwels benodig u/jy iemand wat u/jou gestremde kleinkind aanvaar ten spyte van hoe hy of sy optree</p> <p>1 Benodig nooit hulp hiermee nie                  2 Benodig af en toe hulp hiermee                  3 Benodig soms hulp hiermee                  4 Benodig dikwels hulp hiermee</p>		








7.	<p>Hoe dikwels benodig u/jy iemand om u/jou te help met huishoudelike take</p> <p><i>Score:</i></p> <p>1 Benodig nooit hulp hiermee nie  2 Benodig af en toe hulp hiermee  3 Benodig soms hulp hiermee  4 Benodig dikwels hulp hiermee</p>	
8.	<p>Hoe dikwels benodig u/jy iemand saam met wie u/jy kan ontspan of lag</p> <p><i>Score:</i></p> <p>1 Benodig nooit hulp hiermee nie  2 Benodig af en toe hulp hiermee  3 Benodig soms hulp hiermee  4 Benodig dikwels hulp hiermee</p>	
9.	<p>Hoe dikwels benodig u/jy iemand wat dinge kan doen saam met u/jou gestremde kleinkind</p> <p><i>Score:</i></p> <p>1 Benodig nooit hulp hiermee nie  2 Benodig af en toe hulp hiermee  3 Benodig soms hulp hiermee  4 Benodig dikwels hulp hiermee</p>	
10.	<p>Hoe dikwels benodig u/jy iemand wat vir u/jou of u/jou gestremde kleinkind kan help met vervoer</p> <p><i>Score:</i></p> <p>1 Benodig nooit hulp hiermee nie  2 Benodig af en toe hulp hiermee  3 Benodig soms hulp hiermee  4 Benodig dikwels hulp hiermee</p>	
11.	<p>Hoe dikwels benodig u/jy iemand wat met SASSA (bv. toelae) of hospitaaldienste (bv. terapie of dokterafsprake) kan help wanneer u/jy nie kan nie</p> <p><i>Score:</i></p> <p>1 Benodig nooit hulp hiermee nie  2 Benodig af en toe hulp hiermee  3 Benodig soms hulp hiermee  4 Benodig dikwels hulp hiermee</p>	
12.	<p>Hoe dikwels benodig u/jy iemand wat u/jou meer kan vertel oor dienste vir u/jou gestremde kleinkind of vir u/jou familie</p> <p><i>Score:</i></p> <p>1 Benodig nooit hulp hiermee nie  2 Benodig af en toe hulp hiermee  3 Benodig soms hulp hiermee  4 Benodig dikwels hulp hiermee</p>	

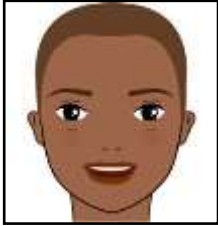




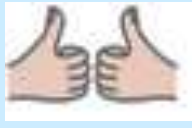











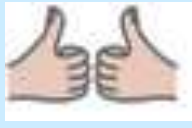
<b>FAMILY SUPPORT SCALE</b>				
<p><b>INSTRUCTIONS:</b> “Nou gaan ons kyk na hoe behulpsaam die mense en groepe is wat u/jou help met die grootmaak van u/jou gestremde kleinkind. Om te kan meet hoeveel hierdie verskillende mense en groepe vir u/jou help, wissel die prentjies van nie beskikbaar tot uiters behulpsaam. Hierdie prentjie beteken dus dat die persoon of groep nie daar is in u/jou lewe nie, hierdie prentjie beteken dat die persoon of groep glad nie behulpsaam is nie, hierdie een beteken dat hulle soms behulpsaam is, en hierdie een beteken dat hulle uiters behulpsaam vir u is. Ons wil bepaal hoe behulpsaam hierdie mense of groepe gedurende die afgelope ses maande vir u/jou was (wys visuele tydskaal op kalender).”</p>				
0	1 	2 	3 	4 
Nie beskikbaar nie	Glad nie behulpsaam nie	Soms behulpsaam	Algemeen behulpsaam	Uiters behulpsaam
1.	<p>Gedurende die afgelope 6 maande, hoe behulpsaam was u/jou man/vrou of lewensmaat</p> <p><i>Score:</i>                      0 Nie beskikbaar nie                      1 Glad nie behulpsaam nie                      2 Soms behulpsaam                      3 Algemeen behulpsaam                      4 Uiters behulpsaam</p>			
				
2.	<p>Gedurende die afgelope 6 maande, hoe behulpsaam was u/jou ouer kind(ers)</p> <p><i>Score:</i>                      0 Nie beskikbaar nie                      1 Glad nie behulpsaam nie                      2 Soms behulpsaam                      3 Algemeen behulpsaam                      4 Uiters behulpsaam</p>			
				
3.	<p>Gedurende die afgelope 6 maande, hoe behulpsaam was u/jou bure</p> <p><i>Score:</i>                      0 Nie beskikbaar nie                      1 Glad nie behulpsaam nie                      2 Soms behulpsaam                      3 Algemeen behulpsaam                      4 Uiters behulpsaam</p>			
				
4.	<p>Gedurende die afgelope 6 maande, hoe behulpsaam was u/jou ouers</p> <p>0 Nie beskikbaar nie                      1 Glad nie behulpsaam nie                      2 Soms behulpsaam                      3 Algemeen behulpsaam                      4 Uiters behulpsaam</p>			
				
5.	<p>Gedurende die afgelope 6 maande, hoe behulpsaam was u/jou ander kleinkinders</p> <p><i>Score:</i>                      0 Nie beskikbaar nie                      1 Glad nie behulpsaam nie                      2 Soms behulpsaam                      3 Algemeen behulpsaam                      4 Uiters behulpsaam</p>			
				

















































<p>6.</p>	<p>Gedurende die afgelope 6 maande, hoe behulpsaam was u/jou familie</p> <p><i>Score:</i>                  0 Nie beskikbaar nie                  1 Glad nie behulpsaam nie                  2 Soms behulpsaam                  3 Algemeen behulpsaam                  4 Uiters behulpsaam</p>	
<p>7.</p>	<p>Gedurende die afgelope 6 maande, hoe behulpsaam was u/jou vriende</p> <p><i>Score:</i>                  0 Nie beskikbaar nie                  1 Glad nie behulpsaam nie                  2 Soms behulpsaam                  3 Algemeen behulpsaam                  4 Uiters behulpsaam</p>	
<p>8.</p>	<p>Gedurende die afgelope 6 maande, hoe behulpsaam was die ouers van u/jou man/vrou of lewensmaat</p> <p><i>Score:</i>                  0 Nie beskikbaar nie                  1 Glad nie behulpsaam nie                  2 Soms behulpsaam                  3 Algemeen behulpsaam                  4 Uiters behulpsaam</p>	
<p>9.</p>	<p>Gedurende die afgelope 6 maande, hoe behulpsaam was die familie van u/jou man/vrou of lewensmaat</p> <p><i>Score:</i>                  0 Nie beskikbaar nie                  1 Glad nie behulpsaam nie                  2 Soms behulpsaam                  3 Algemeen behulpsaam                  4 Uiters behulpsaam</p>	
<p>10.</p>	<p>Gedurende die afgelope 6 maande, hoe behulpsaam was die vriende van u/jou man/vrou of lewensmaat</p> <p><i>Score:</i>                  0 Nie beskikbaar nie                  1 Glad nie behulpsaam nie                  2 Soms behulpsaam                  3 Algemeen behulpsaam                  4 Uiters behulpsaam</p>	
<p>11.</p>	<p>Gedurende die afgelope 6 maande, hoe behulpsaam was u/jou kinderoppasser</p> <p><i>Score:</i>                  0 Nie beskikbaar nie                  1 Glad nie behulpsaam nie                  2 Soms behulpsaam                  3 Algemeen behulpsaam                  4 Uiters behulpsaam</p>	

12.	<p>Gedurende die afgelope 6 maande, hoe behulpsaam was u/jou werkgewer</p> <p><i>Score:</i></p> <p>0 Nie beskikbaar nie</p> <p>1 Glad nie behulpsaam nie</p> <p>2 Soms behulpsaam</p> <p>3 Algemeen behulpsaam</p> <p>4 Uiters behulpsaam</p>	
13.	<p>Gedurende die afgelope 6 maande, hoe behulpsaam was ander oupas en oumas wat hul gestremde kleinkind grootmaak</p> <p><i>Score:</i></p> <p>0 Nie beskikbaar nie</p> <p>1 Glad nie behulpsaam nie</p> <p>2 Soms behulpsaam</p> <p>3 Algemeen behulpsaam</p> <p>4 Uiters behulpsaam</p>	
14.	<p>Gedurende die afgelope 6 maande, hoe behulpsaam was ander oupas en oumas</p> <p><i>Score:</i></p> <p>0 Nie beskikbaar nie</p> <p>1 Glad nie behulpsaam nie</p> <p>2 Soms behulpsaam</p> <p>3 Algemeen behulpsaam</p> <p>4 Uiters behulpsaam</p>	
15.	<p>Gedurende die afgelope 6 maande, hoe behulpsaam was die lede van ondersteuningsgroepe vir oupas en oumas wat versorging doen</p> <p><i>Score:</i></p> <p>0 Nie beskikbaar nie</p> <p>1 Glad nie behulpsaam nie</p> <p>2 Soms behulpsaam</p> <p>3 Algemeen behulpsaam</p> <p>4 Uiters behulpsaam</p>	
16.	<p>Gedurende die afgelope 6 maande, hoe behulpsaam was die mense wat saam met u/jou werk</p> <p><i>Score:</i></p> <p>0 Nie beskikbaar nie</p> <p>1 Glad nie behulpsaam nie</p> <p>2 Soms behulpsaam</p> <p>3 Algemeen behulpsaam</p> <p>4 Uiters behulpsaam</p>	
17.	<p>Gedurende die afgelope 6 maande, hoe behulpsaam was die lede van u/jou sosiale groepe/klubs</p> <p><i>Score:</i></p> <p>0 Nie beskikbaar nie</p> <p>1 Glad nie behulpsaam nie</p> <p>2 Soms behulpsaam</p> <p>3 Algemeen behulpsaam</p> <p>4 Uiters behulpsaam</p>	













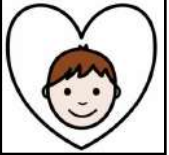





18.	<p>Gedurende die afgelope 6 maande, hoe behulpsaam was die groeplede van u/jou geestelike groepe of u/jou geestelike leiers</p> <p><i>Score:</i></p> <p>0 Nie beskikbaar nie</p> <p>1 Glad nie behulpsaam nie</p> <p>2 Soms behulpsaam</p> <p>3 Algemeen behulpsaam</p> <p>4 Uiters behulpsaam</p>	
19.	<p>Gedurende die afgelope 6 maande, hoe behulpsaam was u/jou gesinsdokter of die dokter van u gestremde kleinkind</p> <p><i>Score:</i></p> <p>0 Nie beskikbaar nie</p> <p>1 Glad nie behulpsaam nie</p> <p>2 Soms behulpsaam</p> <p>3 Algemeen behulpsaam</p> <p>4 Uiters behulpsaam</p>	
20.	<p>Gedurende die afgelope 6 maande, hoe behulpsaam was die versorgingsentrums of dagsorg van u/jou gestremde kleinkind</p> <p><i>Score:</i></p> <p>0 Nie beskikbaar nie</p> <p>1 Glad nie behulpsaam nie</p> <p>2 Soms behulpsaam</p> <p>3 Algemeen behulpsaam</p> <p>4 Uiters behulpsaam</p>	
21.	<p>Gedurende die afgelope 6 maande, hoe behulpsaam was professionele persone (bv. maatskaplike werkers, gemeenskapsrehabilitasiewerkers, terapeute)</p> <p><i>Score:</i></p> <p>0 Nie beskikbaar nie</p> <p>1 Glad nie behulpsaam nie</p> <p>2 Soms behulpsaam</p> <p>3 Algemeen behulpsaam</p> <p>4 Uiters behulpsaam</p>	
22.	<p>Gedurende die afgelope 6 maande, hoe behulpsaam was professionele dienste (verpleegsters, maatskaplike dienste, geestelike gesondheid, ens.)</p> <p><i>Score:</i></p> <p>0 Nie beskikbaar nie</p> <p>1 Glad nie behulpsaam nie</p> <p>2 Soms behulpsaam</p> <p>3 Algemeen behulpsaam</p> <p>4 Uiters behulpsaam</p>	
23.	<p>Wie is die ander mense of groepe wat oor die afgelope 6 maande vir u gehelp het?</p> <p><i>Write on score sheet:</i> _____</p>	

**Appendix J1: Respondent’s Side of Booklet for Each Measure (English)**



















<b>Parental Stress Scale</b>					
1.	You are happy in your role as a caregiver of your grandchild with a disability				
 Strongly disagree		 Disagree	 Undecided	 Agree	 Strongly agree
2.	You would do everything you can for your grandchild with a disability				
 Strongly disagree		 Disagree	 Undecided	 Agree	 Strongly agree
3.	Caring for your grandchild with a disability sometimes takes more time and energy than you have to give.				
 Strongly disagree		 Disagree	 Undecided	 Agree	 Strongly agree













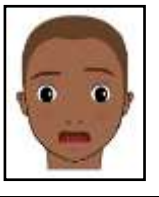





4.	Raising your grandchild with a disability has meant having too little control over your own life.								
<table border="1" style="width: 100%; text-align: center;"> <tr> <td data-bbox="152 386 431 646">  Strongly disagree         </td> <td data-bbox="431 386 704 646">  Disagree         </td> <td data-bbox="704 386 977 646">  Undecided         </td> <td data-bbox="977 386 1250 646">  Agree         </td> <td data-bbox="1250 386 1511 646">  Strongly agree         </td> </tr> </table>					 Strongly disagree	 Disagree	 Undecided	 Agree	 Strongly agree
 Strongly disagree	 Disagree	 Undecided	 Agree	 Strongly agree					
5.	You sometimes worry whether you are doing enough for your grandchild with a disability								
<table border="1" style="width: 100%; text-align: center;"> <tr> <td data-bbox="152 842 431 1102">  Strongly disagree         </td> <td data-bbox="431 842 704 1102">  Disagree         </td> <td data-bbox="704 842 977 1102">  Undecided         </td> <td data-bbox="977 842 1250 1102">  Agree         </td> <td data-bbox="1250 842 1511 1102">  Strongly agree         </td> </tr> </table>					 Strongly disagree	 Disagree	 Undecided	 Agree	 Strongly agree
 Strongly disagree	 Disagree	 Undecided	 Agree	 Strongly agree					
6.	The behaviour of your grandchild with a disability is often stressful to you								
<table border="1" style="width: 100%; text-align: center;"> <tr> <td data-bbox="152 1297 431 1558">  Strongly disagree         </td> <td data-bbox="431 1297 704 1558">  Disagree         </td> <td data-bbox="704 1297 977 1558">  Undecided         </td> <td data-bbox="977 1297 1250 1558">  Agree         </td> <td data-bbox="1250 1297 1511 1558">  Strongly agree         </td> </tr> </table>					 Strongly disagree	 Disagree	 Undecided	 Agree	 Strongly agree
 Strongly disagree	 Disagree	 Undecided	 Agree	 Strongly agree					



















































































7.	You feel close to your grandchild with a disability			
 Strongly disagree	 Disagree	 Undecided	 Agree	 Strongly agree
8.	You enjoy spending time with your grandchild with a disability			
 Strongly disagree	 Disagree	 Undecided	 Agree	 Strongly agree
9.	Your grandchild with a disability is an important source of love for you			
 Strongly disagree	 Disagree	 Undecided	 Agree	 Strongly agree

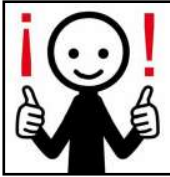





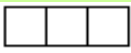


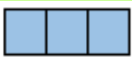
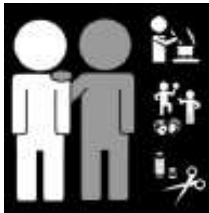





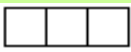






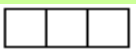


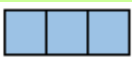

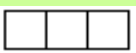


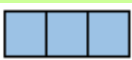
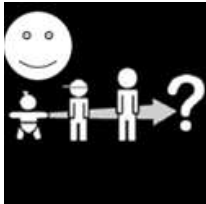
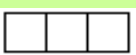


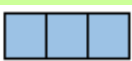

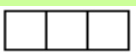


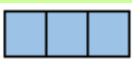
<p>10.</p>	<p>Raising your grandchild with a disability gives you a more certain and positive view for the future</p>			
 <p>Strongly disagree</p>	 <p>Disagree</p>	 <p>Undecided</p>	 <p>Agree</p>	 <p>Strongly agree</p>
<p>11.</p>	<p>The major source of stress in your life is your grandchild with a disability</p>			
 <p>Strongly disagree</p>	 <p>Disagree</p>	 <p>Undecided</p>	 <p>Agree</p>	 <p>Strongly agree</p>
<p>12.</p>	<p>Raising your grandchild with a disability leaves little time and flexibility in your life</p>			
 <p>Strongly disagree</p>	 <p>Disagree</p>	 <p>Undecided</p>	 <p>Agree</p>	 <p>Strongly agree</p>


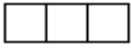




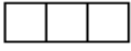




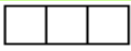




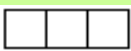


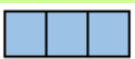
13.	Raising your grandchild with a disability is a financial burden			
 Strongly disagree	 Disagree	 Undecided	 Agree	 Strongly agree
14.	It is difficult to balance different responsibilities because of your grandchild with a disability			
 Strongly disagree	 Disagree	 Undecided	 Agree	 Strongly agree
15.	The behaviour of your grandchild with a disability is often embarrassing to you			
 Strongly disagree	 Disagree	 Undecided	 Agree	 Strongly agree


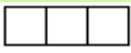




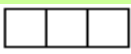

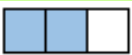
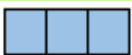

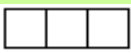

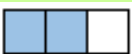
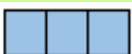

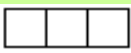


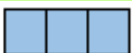
<p>16.</p>	<p>If you had it to do over again, you might decide not to raise your grandchild with a disability</p>								
<table border="1" style="width: 100%; text-align: center;"> <tr> <td data-bbox="152 352 431 615">                       Strongly disagree                 </td> <td data-bbox="431 352 704 615">                       Disagree                 </td> <td data-bbox="704 352 977 615">                       Undecided                 </td> <td data-bbox="977 352 1250 615">                       Agree                 </td> <td data-bbox="1250 352 1502 615">                       Strongly agree                 </td> </tr> </table>					 Strongly disagree	 Disagree	 Undecided	 Agree	 Strongly agree
 Strongly disagree	 Disagree	 Undecided	 Agree	 Strongly agree					
<p>17.</p>	<p>You feel overwhelmed by the responsibility of being a caregiver to your grandchild with a disability</p>								
<table border="1" style="width: 100%; text-align: center;"> <tr> <td data-bbox="152 810 431 1068">                       Strongly disagree                 </td> <td data-bbox="431 810 704 1068">                       Disagree                 </td> <td data-bbox="704 810 977 1068">                       Undecided                 </td> <td data-bbox="977 810 1250 1068">                       Agree                 </td> <td data-bbox="1250 810 1502 1068">                       Strongly agree                 </td> </tr> </table>					 Strongly disagree	 Disagree	 Undecided	 Agree	 Strongly agree
 Strongly disagree	 Disagree	 Undecided	 Agree	 Strongly agree					
<p>18.</p>	<p>Raising your grandchild with a disability has meant having too few choices</p>								
<table border="1" style="width: 100%; text-align: center;"> <tr> <td data-bbox="152 1276 431 1528">                       Strongly disagree                 </td> <td data-bbox="431 1276 704 1528">                       Disagree                 </td> <td data-bbox="704 1276 977 1528">                       Undecided                 </td> <td data-bbox="977 1276 1250 1528">                       Agree                 </td> <td data-bbox="1250 1276 1502 1528">                       Strongly agree                 </td> </tr> </table>					 Strongly disagree	 Disagree	 Undecided	 Agree	 Strongly agree
 Strongly disagree	 Disagree	 Undecided	 Agree	 Strongly agree					

19.	You are satisfied as a grandparent								
<table border="1" style="width: 100%; text-align: center;"> <tr> <td data-bbox="147 386 431 648">                       Strongly disagree                 </td> <td data-bbox="431 386 704 648">                       Disagree                 </td> <td data-bbox="704 386 977 648">                       Undecided                 </td> <td data-bbox="977 386 1250 648">                       Agree                 </td> <td data-bbox="1250 386 1526 648">                       Strongly agree                 </td> </tr> </table>					 Strongly disagree	 Disagree	 Undecided	 Agree	 Strongly agree
 Strongly disagree	 Disagree	 Undecided	 Agree	 Strongly agree					
20.	You find your grandchild with a disability enjoyable								
<table border="1" style="width: 100%; text-align: center;"> <tr> <td data-bbox="147 863 431 1125">                       Strongly disagree                 </td> <td data-bbox="431 863 704 1125">                       Disagree                 </td> <td data-bbox="704 863 977 1125">                       Undecided                 </td> <td data-bbox="977 863 1250 1125">                       Agree                 </td> <td data-bbox="1250 863 1526 1125">                       Strongly agree                 </td> </tr> </table>					 Strongly disagree	 Disagree	 Undecided	 Agree	 Strongly agree
 Strongly disagree	 Disagree	 Undecided	 Agree	 Strongly agree					


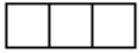




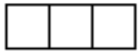
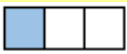



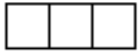


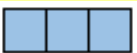
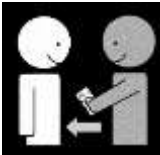
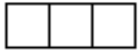


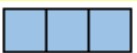
Personal Well-Being Index				
1.	Since the beginning of the month/past 2 weeks how often have you felt that your life is going just great			
	 You never felt like this	 You felt this once in a while	 You sometimes felt this	 You often felt this
2.	Since the beginning of the month/past 2 weeks how often have you felt trapped by your responsibilities as a caregiver of your grandchild with a disability			
	 You never felt like this	 You felt this once in a while	 You sometimes felt this	 You often felt this
3.	Since the beginning of the month/past 2 weeks how often have you found it easy to physically take care of your grandchild with a disability			
	 You never felt like this	 You felt this once in a while	 You sometimes felt this	 You often felt this
4.	Since the beginning of the month/past 2 weeks how often have you felt unwell or ill			
	 You never felt like this	 You felt this once in a while	 You sometimes felt this	 You often felt this

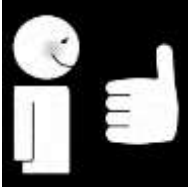
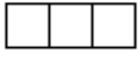




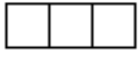









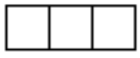
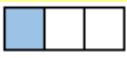

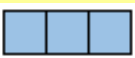
5.	Since the beginning of the month/past 2 weeks how often have you felt uneasy or scared without knowing why			
 You never felt like this		 You felt this once in a while	 You sometimes felt this	 You often felt this
6.	Since the beginning of the month/past 2 weeks how often have you felt tired or exhausted after caring for your grandchild with a disability			
 You never felt like this		 You felt this once in a while	 You sometimes felt this	 You often felt this
7.	Since the beginning of the month/past 2 weeks how often have you felt glad about your grandchild with a disability's future			
 You never felt like this		 You felt this once in a while	 You sometimes felt this	 You often felt this
8.	Since the beginning of the month/past 2 weeks how often have you felt tired or run-down			
 You never felt like this		 You felt this once in a while	 You sometimes felt this	 You often felt this


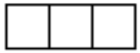


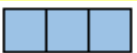
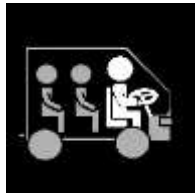





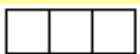
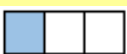



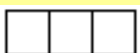



<p>9.</p>	<p>Since the beginning of the month/past 2 weeks how often have you seen no end to the demands your grandchild with a disability makes on you</p>						
<p> You never felt like this</p>		<p> You felt this once in a while</p>		<p> You sometimes felt this</p>		<p> You often felt this</p>	
<p>10.</p>	<p>Since the beginning of the month/past 2 weeks how often have you had lots of energy to get things done (e.g. household chores)</p>						
<p> You never felt like this</p>		<p> You felt this once in a while</p>		<p> You sometimes felt this</p>		<p> You often felt this</p>	
<p>11.</p>	<p>Since the beginning of the month/past 2 weeks how often have you felt down or depressed</p>						
<p> You never felt like this</p>		<p> You felt this once in a while</p>		<p> You sometimes felt this</p>		<p> You often felt this</p>	
<p>12.</p>	<p>Since the beginning of the month/past 2 weeks how often have you had lots of energy to keep up with your grandchild with a disability</p>						
<p> You never felt like this</p>		<p> You felt this once in a while</p>		<p> You sometimes felt this</p>		<p> You often felt this</p>	





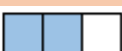
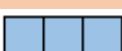



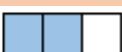
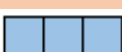



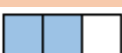
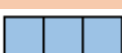



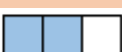
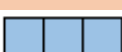
<p>13.</p>	<p>Since the beginning of the month/past 2 weeks how often have you found pleasure in the things your grandchild with a disability does</p>		
<p> You never felt like this</p>	<p> You felt this once in a while</p>	<p> You sometimes felt this</p>	<p> You often felt this</p>
<p>14.</p>	<p>Since the beginning of the month/past 2 weeks how often have you felt really happy</p>		
<p> You never felt like this</p>	<p> You felt this once in a while</p>	<p> You sometimes felt this</p>	<p> You often felt this</p>
<p>15.</p>	<p>Since the beginning of the month/past 2 weeks how often have you found that caring for your grandchild with a disability puts a strain on you</p>		
<p> You never felt like this</p>	<p> You felt this once in a while</p>	<p> You sometimes felt this</p>	<p> You often felt this</p>
<p>16.</p>	<p>Since the beginning of the month/past 2 weeks how often have you been feeling like you are in great shape</p>		
<p> You never felt like this</p>	<p> You felt this once in a while</p>	<p> You sometimes felt this</p>	<p> You often felt this</p>



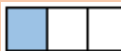
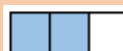
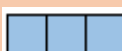



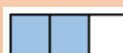
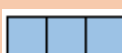



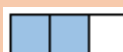



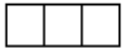

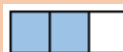
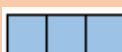







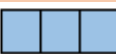


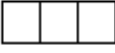

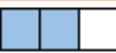
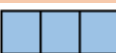

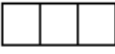

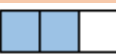


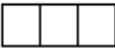

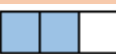

Support Functions Scale				
1.	How often do you feel you need someone to talk to about things that worry you			
	 You never need this help	 You need this help once in a while	 You sometimes need this help	 You need this help quite often
2.	How often do you feel you need someone to help take care of your grandchild with a disability			
	 You never need this help	 You need this help once in a while	 You sometimes need this help	 You need this help quite often
3.	How often do you feel you need someone to talk to when you have questions about raising your grandchild with a disability			
	 You never need this help	 You need this help once in a while	 You sometimes need this help	 You need this help quite often
4.	How often do you feel you need someone who can lend you money when you need it			
	 You never need this help	 You need this help once in a while	 You sometimes need this help	 You need this help quite often

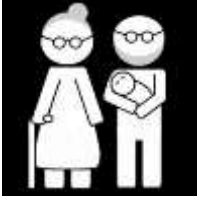


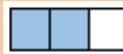
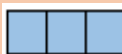




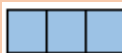



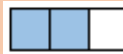
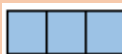
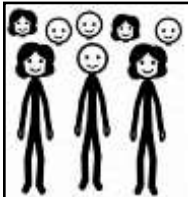
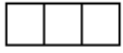



5.	How often do you feel you need someone to encourage or keep you going when things seem hard			
 You never need this help		 You need this help once in a while	 You sometimes need this help	 You need this help quite often
6.	How often do you feel you need someone who accepts your grandchild with a disability regardless of how he or she acts			
 You never need this help		 You need this help once in a while	 You sometimes need this help	 You need this help quite often
7.	How often do you feel you need someone to help you with household chores			
 You never need this help		 You need this help once in a while	 You sometimes need this help	 You need this help quite often
8.	How often do you feel you need someone with whom you can relax or laugh with			
 You never need this help		 You need this help once in a while	 You sometimes need this help	 You need this help quite often
(Empty row for additional content)				


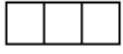

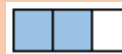
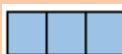
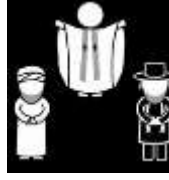
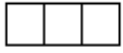

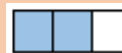




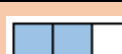
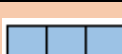

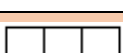

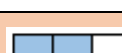
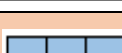
9.	How often do you feel you need someone to do things with your grandchild with a disability			
 You never need this help		 You need this help once in a while	 You sometimes need this help	 You need this help quite often
10.	How often do you feel you need someone to help your grandchild with a disability or you with transportation			
 You never need this help		 You need this help once in a while	 You sometimes need this help	 You need this help quite often
11.	How often do you feel you need someone to follow up with SASSA (e.g. grants) or hospital services (e.g. therapy/doctor appointments) when you can't			
 You never need this help		 You need this help once in a while	 You sometimes need this help	 You need this help quite often
12.	How often do you feel you need someone who can tell you about services for your grandchild with a disability or your family			
 You never need this help		 You need this help once in a while	 You sometimes need this help	 You need this help quite often

Family Support Scale					
1.	Since the past 6 months how helpful has <b>your husband/wife</b> or partner been				
Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful	
2.	Since the past 6 months how helpful have your older child(ren) been				
Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful	
3.	Since the past 6 months how helpful have your neighbours been				
Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful	
4.	Since the past 6 months how helpful have your parents been				
Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful	


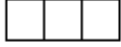




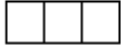


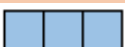
5.	Since the past 6 months how helpful have your other grandchildren have been				
Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful	
6.	Since the past 6 months how helpful have your relatives been				
Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful	
7.	Since the past 6 months how helpful have your friends been				
Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful	
8.	Since the past 6 months how helpful have the <b>parents of your husband/wife</b> or partner been				
Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful	

9.	Since the past 6 months how helpful have the <b>relatives of your husband/wife</b> or partner been				
Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful	
10.	Since the past 6 months how helpful have the <b>friends of your husband/wife</b> or partner been				
Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful	
11.	Since the past 6 months how helpful has your nanny been				
Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful	
12.	Since the past 6 months how helpful has your employer been				
Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful	



















13.	Since the past 6 months how helpful have other grandparents raising their grandchild with a disability been				
Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful	
14.	Since the past 6 months how helpful have other grandparents been				
Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful	
15.	Since the past 6 months how helpful have members of grandparent caregivers support group been				
Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful	
16.	Since the past 6 months how helpful have your co-workers been				
Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful	

























17.	Since the past 6 months how helpful have members of your social groups/clubs been				
Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful	
18.	Since the past 6 months how helpful have your fellow religious group members or spiritual leaders been				
Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful	
19.	Since the past 6 months how helpful has your family doctor or the doctor of your grandchild with a disability been				
Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful	
20.	Since the past 6 months how helpful has your grandchild with a disability's care centres/crèche been				
Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful	



















































21.	Since the past 6 months how helpful have professional helpers (e.g. social worker, community rehab worker, therapists) been				
Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful	
22.	Since the past 6 months how helpful have professional services (nurses, social services, mental health etc.) been				
Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful	

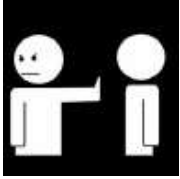

















**Appendix J2: Respondent's Side of Booklet for Each Measure (IsiXhosa)**













Parent Stress Scale					
1.	Wonwabile kwindima yakho njengomzali nomnakekeli womzukulwana wakho okhubazekileyo				
					
Andivumi konke konke	Andivumi	Andinasigqibo	Ndiyavuma	Ndiyavuma kakhulu	
2.	Ungenza konke onako ngomzukulwana wakho okhubazekileyo				
					
Andivumi konke konke	Andivumi	Andinasigqibo	Ndiyavuma	Ndiyavuma kakhulu	
3.	Ukunakekela umzukulwana okhubazekileyo kuthatha ixesha elinzi namandla ngaphezulu kokuba unako				
					
Andivumi konke konke	Andivumi	Andinasigqibo	Ndiyavuma	Ndiyavuma kakhulu	

<p>4.</p>	<p>Ukukhulisa umzukulwana okhubazekileyo kuthetha ukuba unolawulo oluncinci ngobomi bakho</p>			
 <p>Andivumi konke konke</p>	 <p>Andivumi</p>	 <p>Andinasigqibo</p>	 <p>Ndiyavuma</p>	 <p>Ndiyavuma kakhulu</p>
<p>5.</p>	<p>Ngamaxesha ubanexhala lokuba ingaba wenza okwaneleyo kumzukulwana wakho okhubazekileyo</p>			
 <p>Andivumi konke konke</p>	 <p>Andivumi</p>	 <p>Andinasigqibo</p>	 <p>Ndiyavuma</p>	 <p>Ndiyavuma kakhulu</p>
<p>6.</p>	<p>Indlela aziphatha ngayo umzukulwana wakho okhubazekileyo amaxesha amaninzi yenza uxinzelelo</p>			
 <p>Andivumi konke konke</p>	 <p>Andivumi</p>	 <p>Andinasigqibo</p>	 <p>Ndiyavuma</p>	 <p>Ndiyavuma kakhulu</p>
<p>7.</p>	<p>Uziva usondele kumzukulwana wakho okhubazekileyo</p>			
 <p>Andivumi konke konke</p>	 <p>Andivumi</p>	 <p>Andinasigqibo</p>	 <p>Ndiyavuma</p>	 <p>Ndiyavuma kakhulu</p>







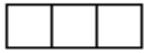



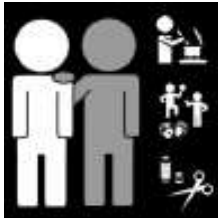
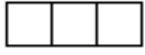



8.	Uyakonwabela ukuchitha ixesha nomzukulwana wakho okhubazekileyo			
 Andivumi konke konke	 Andivumi	 Andinasigqibo	 Ndiyavuma	 Ndiyavuma kakhulu
9.	Umzukulwana wakho okhubazekileyo ungumthobo obabulekilyo wothando kuwe			
 Andivumi konke konke	 Andivumi	 Andinasigqibo	 Ndiyavuma	 Ndiyavuma kakhulu
10.	Ukukhulisa umzukulwana wakho okhubazekileyo kunika isiqinisekiso nombono omhle ngekamva			
 Andivumi konke konke	 Andivumi	 Andinasigqibo	 Ndiyavuma	 Ndiyavuma kakhulu
11.	Ewona mthombo woxinzelelo ebomini bakho ngumzukulwana wakho okhubazekileyo			
 Andivumi konke konke	 Andivumi	 Andinasigqibo	 Ndiyavuma	 Ndiyavuma kakhulu

12.	Ukukhulisa umzukulwana wakho okhubazekileyo kukushiya unexeshana lentshukumo ebomini bakho			
 Andivumi konke konke	 Andivumi	 Andinasigqibo	 Ndiyavuma	 Ndiyavuma kakhulu
13.	Ukukhulisa umzukulwana okhubazekileyo kungumthwalo kuwe ngokwasezimalini			
 Andivumi konke konke	 Andivumi	 Andinasigqibo	 Ndiyavuma	 Ndiyavuma kakhulu
14.	Kunzima ukulinganisa nokwenza lonke uxanduva lwakho ngenxa yomzukulwana wakho okhubazekileyo			
 Andivumi konke konke	 Andivumi	 Andinasigqibo	 Ndiyavuma	 Ndiyavuma kakhulu
15.	Indlela aziphatha ngayo umzukulwana wakho okhubazekileyo amaxesha amaninzi yenza iintloni.			
 Andivumi konke konke	 Andivumi	 Andinasigqibo	 Ndiyavuma	 Ndiyavuma kakhulu


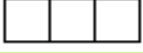
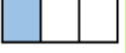



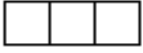
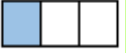


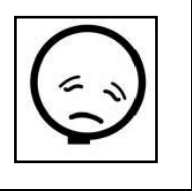

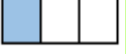


<p>16.</p>	<p>Ukuba bekufuneka uphinde wenze oku ukwenzile ngomzukulwana wakho okhubazekileyo ubunokhetha ukungamkhulisi na umzukulwana wakho</p>			
 <p>Andivumi konke konke</p>	 <p>Andivumi</p>	 <p>Andinasigqibo</p>	 <p>Ndiyavuma</p>	 <p>Ndiyavuma kakhulu</p>
<p>17.</p>	<p>Uziva ugubungekile luxanduva loba ngumzali womzukulwana okhubazekileyo</p>			
 <p>Andivumi konke konke</p>	 <p>Andivumi</p>	 <p>Andinasigqibo</p>	 <p>Ndiyavuma</p>	 <p>Ndiyavuma kakhulu</p>
<p>18.</p>	<p>Ukukhulisa umzukulwana okhubazekileyo kuthetha ukuba abathuba akho ambalwa</p>			
 <p>Andivumi konke konke</p>	 <p>Andivumi</p>	 <p>Andinasigqibo</p>	 <p>Ndiyavuma</p>	 <p>Ndiyavuma kakhulu</p>
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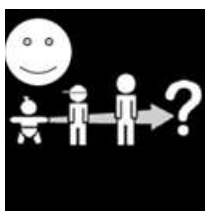

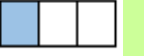






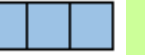

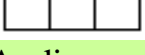
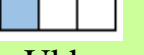
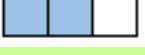
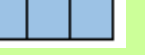
<p>19.</p>	<p>Uyaneliseka njengomakhulu</p>				
 <p>Andivumi konke konke</p>	 <p>Andivumi</p>	 <p>Andinasigqibo</p>	 <p>Ndiyavuma</p>	 <p>Ndiyavuma kakhulu</p>	
<p>20.</p>	<p>Ufumanisa kukonwabisa na ukuba nomzukulwana wakho onokhubazeko.</p>				
 <p>Andivumi konke konke</p>	 <p>Andivumi</p>	 <p>Andinasigqibo</p>	 <p>Ndiyavuma</p>	 <p>Ndiyavuma kakhulu</p>	


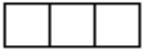


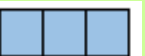

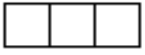


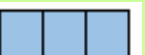

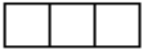


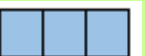



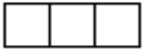


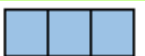

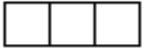


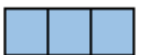

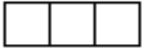




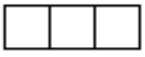


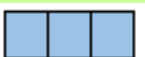
Personal Well-Being Index					
1.	<p>Ukususela ekuqalekeni kwenyanga/okanye kwiiveki ezimbini ukhe waziva ngathi ubomi bakho buhamba nje kakuhle</p>				
	 <p>Andizange ndanemvakalelo ezinje</p>	 <p>Ukhe ubeneemvakalelo ezinje emva kwexesha elide</p>	 <p>Ukhe ubenemvakalelo ezinje ngamanye amaxesha</p>	 <p>Ukhe ubenezi mvakalelo ngamanye amaxesha</p>	
2.	<p>Ukusukela ekuqalekeni kwenyanga/okanye kwiiveki ezimbini kukangakanani usiva ngathi ubambekile kuxanduva lokunakekela umzukulwana wakho onokhubazeko</p>				
	 <p>Andizange ndanemvakalelo ezinje</p>	 <p>Ukhe ubeneemvakalelo ezinje emva kwexesha elide</p>	 <p>Ukhe ubenemvakalelo ezinje ngamanye amaxesha</p>	 <p>Ukhe ubenezi mvakalelo ngamanye amaxesha</p>	
3.	<p>Ukusukela ekuqalekeni kwenyanga /okanye kwiiveki ezimbini ingaba ufumanise kulula namandla okunakekela umzukulwana wakho onokhubazeko</p>				
	 <p>Andizange ndanemvakalelo ezinje</p>	 <p>Ukhe ubeneemvakalelo ezinje emva kwexesha elide</p>	 <p>Ukhe ubenemvakalelo ezinje ngamanye amaxesha</p>	 <p>Ukhe ubenezi mvakalelo ngamanye amaxesha</p>	

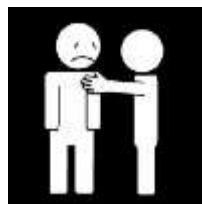





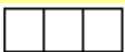









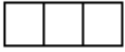


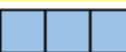



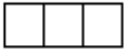



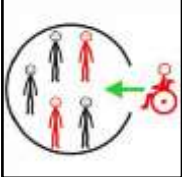
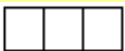

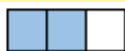


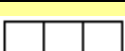




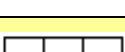



4.	Ukusukela ekuqalekeni kwenyanga/okanye iiveki ezimbini ezidlulileyo ingaba ukhe wangaziva mnandi okanye ungaphilanga		
 Andizange ndanemvakalelo ezinje	 Ukhe ubeneemvakalelo ezinje emva kwexesha elide	 Ukhe ubenemvakalelo ezinje ngamanye amaxesha	 Ukhe ubenezi mvakalelo ngamanye amaxesha
5.	Ukusukela ekuqaleni kwenyanga/okanye iiveki ezimbini ezidlulileyominga ukhe waziva kungelula okanye unoloyiko ongalwaziyo ukuba lolwantoni na		
 Andizange ndanemvakalelo ezinje	 Ukhe ubeneemvakalelo ezinje emva kwexesha elide	 Ukhe ubenemvakalelo ezinje ngamanye amaxesha	 Ukhe ubenezi mvakalelo ngamanye amaxesha
6.	Ukusukela ukuqala kwenyanga/okanye iiveki ezimbini ezidlulieyo ingaba ukhe waziva unokudinwa nokudineka emva kokunakekela umzukulwana wakho onokhubazeko		
 Andizange ndanemvakalelo ezinje	 Ukhe ubeneemvakalelo ezinje emva kwexesha elide	 Ukhe ubenemvakalelo ezinje ngamanye amaxesha	 Ukhe ubenezi mvakalelo ngamanye amaxesha
(Empty shaded area)			

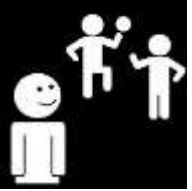
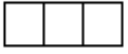


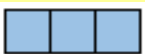

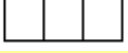
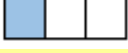
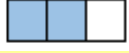


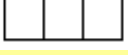
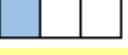



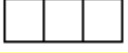
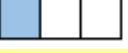


7.	<p>Ukusukela ukuqala kwenyanga /okanye kwiiveki ezimbini ezidlulileyo ingaba kukangaphi apho uthe waziva wonwabile ngumzukulwana wakho nekamva lakhe</p>		
<p> Andizange ndanemvakalelo ezinje</p>	<p> Ukhe ubeneemvakalelo ezinje emva kwexesha elide</p>	<p> Ukhe ubenemvakalelo ezinje ngamanye amaxesha</p>	<p> Ukhe ubenezi mvakalelo ngamanye amaxesha</p>
8.	<p>Ukusukela ukuqala kwenyanga okanye iiveki ezimbini ezidlulileyo ngaba ukhe waziva ukudinwa okanye uphantsi na</p>		
<p> Andizange ndanemvakalelo ezinje</p>	<p> Ukhe ubeneemvakalelo ezinje emva kwexesha elide</p>	<p> Ukhe ubenemvakalelo ezinje ngamanye amaxesha</p>	<p> Ukhe ubenezi mvakalelo ngamanye amaxesha</p>
9.	<p>Ukusukela ekuqaleni kwenyanga okanye kwiiveki ezimbini ezidlulileyo ingaba ukhe weva ukuba iimfuno zomzukulwana wakho onokhubazeko azifikeleli esiphelweni na</p>		
<p> Andizange ndanemvakalelo ezinje</p>	<p> Ukhe ubeneemvakalelo ezinje emva kwexesha elide</p>	<p> Ukhe ubenemvakalelo ezinje ngamanye amaxesha</p>	<p> Ukhe ubenezi mvakalelo ngamanye amaxesha</p>
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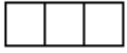


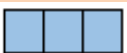

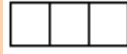


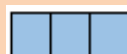



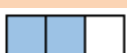
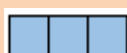
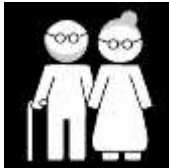


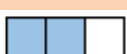

10.	<p>Ukusukela ukuqala kwenyanga okanye iiveki ezimbini ezidlulileyo ukhe wazifumanisa unamandla awaneleyo na ukwenza izinto ezininzi ezinje ngomsebenzi wasekhaya</p>		
<p> Andizange ndanemvakalelo ezinje</p>	<p> Ukhe ubeneemvakalelo ezinje emva kwexesha elide</p>	<p> Ukhe ubenemvakalelo ezinje ngamanye amaxesha</p>	<p> Ukhe ubenezi mvakalelo ngamanye amaxesha</p>
11.	<p>Ukusukela ekuqaleni kwenyanga okanye kwiiveki ezimbini ezidlulileyo ingaba ukhe waziva unompya ophantsi kwakunye noxinizelelo olukhulu lwengqondo</p>		
<p> Andizange ndanemvakalelo ezinje</p>	<p> Ukhe ubeneemvakalelo ezinje emva kwexesha elide</p>	<p> Ukhe ubenemvakalelo ezinje ngamanye amaxesha</p>	<p> Ukhe ubenezi mvakalelo ngamanye amaxesha</p>
12.	<p>Ukusukela ekuqaleni kwenyanga okanye kwiiveki ezimbini ezidlulileyo ingaba ukhe wanamaxesha okuziva unamandla amakhulu okunakekela umzukulwana wakho onokhubazeko</p>		
<p> Andizange ndanemvakalelo ezinje</p>	<p> Ukhe ubeneemvakalelo ezinje emva kwexesha elide</p>	<p> Ukhe ubenemvakalelo ezinje ngamanye amaxesha</p>	<p> Ukhe ubenezi mvakalelo ngamanye amaxesha</p>

13.	<p>Ukusukela ekuqaleni kwenyanga okanye kwiiveki ezimbini ezidlulileyo ingaba uye wafumana ukuzonwabela izinto ezithile ezenziwa ngumzukulwana wakho onokhubazeko</p>		
<p> Andizange ndanemvakalelo ezinje</p>	<p> Ukhe ubeneemvakalelo ezinje emva kwexesha elide</p>	<p> Ukhe ubenemvakalelo ezinje ngamanye amaxesha</p>	<p> Ukhe ubenezi mvakalelo ngamanye amaxesha</p>
14.	<p>Ukususela ekuqalekeni kwenyanga okanye kwiiveki ezimbini ezidlulileyo ingaba ukhe waziva nohulumanco olukhulu</p>		
<p> Andizange ndanemvakalelo ezinje</p>	<p> Ukhe ubeneemvakalelo ezinje emva kwexesha elide</p>	<p> Ukhe ubenemvakalelo ezinje ngamanye amaxesha</p>	<p> Ukhe ubenezi mvakalelo ngamanye amaxesha</p>
15.	<p>Ukususela ekuqalekeni kwenyanga okanye kwiiveki ezimbini ezidlulileyo ukhe wafumanisa ukuba ukunakekela umzukulwana wakho onokubazeko kukufakela uxinizelelo olukhulu</p>		
<p> Andizange ndanemvakalelo ezinje</p>	<p> Ukhe ubeneemvakalelo ezinje emva kwexesha elide</p>	<p> Ukhe ubenemvakalelo ezinje ngamanye amaxesha</p>	<p> Ukhe ubenezi mvakalelo ngamanye amaxesha</p>
16.	<p>Ukususela ekuqalekeni kwenyanga okanye kwiiveki ezimbini ezidlulileyo ingaba ukhe waziva usemandleni kakhulu</p>		
<p> Andizange ndanemvakalelo ezinje</p>	<p> Ukhe ubeneemvakalelo ezinje emva kwexesha elide</p>	<p> Ukhe ubenemvakalelo ezinje ngamanye amaxesha</p>	<p> Ukhe ubenezi mvakalelo ngamanye amaxesha</p>


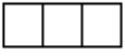




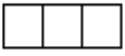

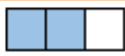


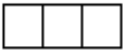

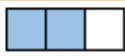

Support Functions Scale				
1.	Kukangapi uziva ufuna ukuthetha nomntu malunga nezinto ezikubangela inkxalabo			
	 Awuzange wakhe walufuna olu uncedo	 Ukhe ulufune oluncedo ngamaxesha athile	 Ngamaxesha athile ukhe ulufune olu ncedo	 Ulufuna olu ncedo ngamaxesha onke
2.	Kukangaphi uziva ufuna umntu wokukuncedisa ekunakekeleni umzukulwana wakho onokhubazeko			
	 Awuzange wakhe walufuna olu uncedo	 Ukhe ulufune oluncedo ngamaxesha athile	 Ngamaxesha athile ukhe ulufune olu ncedo	 Ulufuna olu ncedo ngamaxesha onke
3.	Kukanagaphi uziva ufuna umntu onokuthetha naye xa unemibuzo malunga nokukhulisa umzukuulwana wakho onokhubazeko			
	 Awuzange wakhe walufuna olu uncedo	 Ukhe ulufune oluncedo ngamaxesha athile	 Ngamaxesha athile ukhe ulufune olu ncedo	 Ulufuna olu ncedo ngamaxesha onke
4.	Kukangaphi uziva ufuna umntu onokuthi akuboleke imali xa uyifuna			
	 Awuzange wakhe walufuna olu uncedo	 Ukhe ulufune oluncedo ngamaxesha athile	 Ngamaxesha athile ukhe ulufune olu ncedo	 Ulufuna olu ncedo ngamaxesha onke



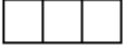
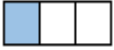
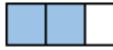



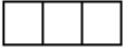

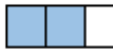



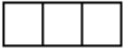

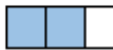

5.	Kukangaphi uziva ufuna umntu onokuthi akukhuthaze akuvuselela xa izinto zinobunzima		
 Awuzange wakhe walufuna olu uncedo	 Ukhe ulufune oluncedo ngamaxesha athile	 Ngamaxesha athile ukhe ulufune olu ncedo	 Ulufuna olu ncedo ngamaxesha onke
6.	Kukangaphi uziva ufuna umntu onokwamkela umzukulwana wakho onokhubazeko nangeendlela enza ngazo izinto		
 Awuzange wakhe walufuna olu uncedo	 Ukhe ulufune oluncedo ngamaxesha athile	 Ngamaxesha athile ukhe ulufune olu ncedo	 Ulufuna olu ncedo ngamaxesha onke
7.	Kukangaphi uziva ufuna umntu wokuncedisa kwimisebenzi yekhaya		
 Awuzange wakhe walufuna olu uncedo	 Ukhe ulufune oluncedo ngamaxesha athile	 Ngamaxesha athile ukhe ulufune olu ncedo	 Ulufuna olu ncedo ngamaxesha onke
8.	Kukangaphi uziva ufuna umntu onokthi uphumle kwaye uhleke naye		
 Awuzange wakhe walufuna olu uncedo	 Ukhe ulufune oluncedo ngamaxesha athile	 Ngamaxesha athile ukhe ulufune olu ncedo	 Ulufuna olu ncedo ngamaxesha onke


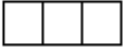




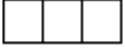



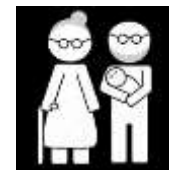
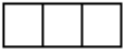


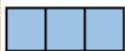




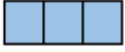
9.	Kukangaphi uziva ufuna umntu onokuthi enze izinto kunye nomzukulwana wakho onokhubazeko		
 Awuzange wakhe walufuna olu uncedo	 Ukhe ulufune oluncedo ngamaxesha athile	 Ngamaxesha athile ukhe ulufune olu ncedo	 Ulufuna olu ncedo ngamaxesha onke
10.	Kukangaphi uziva ufuna umntu onokukunceda ngomzukulwana wakho onokhubazeko okanye wena ngeenkonzozothutho		
 Awuzange wakhe walufuna olu uncedo	 Ukhe ulufune oluncedo ngamaxesha athile	 Ngamaxesha athile ukhe ulufune olu ncedo	 Ulufuna olu ncedo ngamaxesha onke
11.	Kukanganani uziva ufuna umntu onokuthi alandelele ngeenkonzozemali SASSA (umzekelo inkxaso zemali) isibhedlele iinkonzozempilo (umzekelo unyango, ukubonana nogqirha) xa wena ungenako		
 Awuzange wakhe walufuna olu uncedo	 Ukhe ulufune oluncedo ngamaxesha athile	 Ngamaxesha athile ukhe ulufune olu ncedo	 Ulufuna olu ncedo ngamaxesha onke
12.	Kukanganani uziva ufuna umntu onokuthi akuxelele ngeenkonzomalunga nomzukulwana wakho onokhubazeko		
 Awuzange wakhe walufuna olu uncedo	 Ukhe ulufune oluncedo ngamaxesha athile	 Ngamaxesha athile ukhe ulufune olu ncedo	 Ulufuna olu ncedo ngamaxesha onke


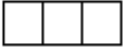


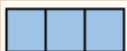

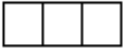





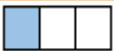
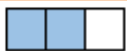

<b>FAMILY SUPPORT SCALE</b>					
1.	Ukususela kwinyanga ezintandathu ezidlulileyo ingaba luncedo olungakanani ubulufumana kumyeni okanye kuknosikazi okanye umlingano				 
Alukho	 Alukho uncedo konke konke	 Uluncedo ngamanye amaxesha	 Uluncedo	 Uluncedo kahulu	
2.	Ukususela kwinyanga ezintandathu ezidlulileyo ingaba belulungakanani na uncedo obulufumana kubantwana bakho abadala				
Alukho	 Alukho uncedo konke konke	 Uluncedo ngamanye amaxesha	 Uluncedo	 Uluncedo kahulu	
3.	Ukususela kwiinyanga ezintandathu ezidlulileyo abamelwana bakho bebekuncedisa kangakanani na				
Alukho	 Alukho uncedo konke konke	 Uluncedo ngamanye amaxesha	 Uluncedo	 Uluncedo kahulu	
4.	Ukususela kwiinyanga ezintandathu ezidlulileyo bebekuncedisa kangakanani na abazali bakho				
Alukho	 Alukho uncedo konke konke	 Uluncedo ngamanye amaxesha	 Uluncedo	 Uluncedo kahulu	

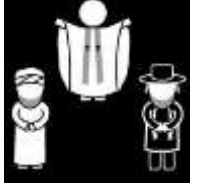
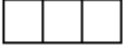











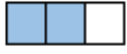




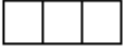
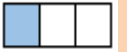


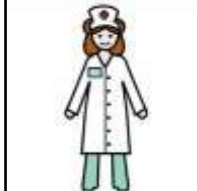
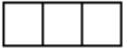



5.	Ukususela kwiinyanga ezintandathu ezidlulileyo ingaba belulungakanani uncedo ubulifumana kubazukulwana bakho			
Alukho	 Alukho uncedo konke konke	 Uluncedo ngamanye amaxesha	 Uluncedo	 Uluncedo kahulu
6.	Ukususela kwiinyanga ezintandathu ezidlulileyo ingaba beziluncedo olungakanani na izizalwana zakho			
Alukho	 Alukho uncedo konke konke	 Uluncedo ngamanye amaxesha	 Uluncedo	 Uluncedo kahulu
7.	Ukususela kwiinyanga ezintandathu ezidlulileyo ingaba beziluncedo olungakanani na izihlobo zakho			
Alukho	 Alukho uncedo konke konke	 Uluncedo ngamanye amaxesha	 Uluncedo	 Uluncedo kahulu

8.	<p>Ukusesela kwiintanga ezintandathu ezidlulileyo ingaba ebeluncedo olungakanani na umyeni wakho/ okanye unkosikazi okanye umlingane wakho</p>			
Alukho	 <p>Alukho uncedo konke konke</p>	 <p>Uluncedo ngamanye amaxesha</p>	 <p>Uluncedo</p>	 <p>Uluncedo kahulu</p>
9.	<p>Ukususela kwiinyanga ezintandathu ezidlulileyo ingaba beziluncedo kangakanani na izihlobo zakulomyeni wakho/ okanye unkosikazi wakho okanye umlingane wakho</p>			
Alukho	 <p>Alukho uncedo konke konke</p>	 <p>Uluncedo ngamanye amaxesha</p>	 <p>Uluncedo</p>	 <p>Uluncedo kahulu</p>
10.	<p>Ukususela kwiinyanga ezintandathu ezidlulileyo ingaba beziluncedo kangakanani na izihlobo zomyeni wakho</p>			
Alukho	 <p>Alukho uncedo konke konke</p>	 <p>Uluncedo ngamanye amaxesha</p>	 <p>Uluncedo</p>	 <p>Uluncedo kahulu</p>






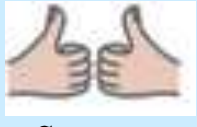





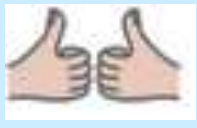





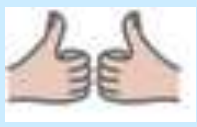
11.	<p>Ukususela kwinyanga ezintandathu ezidlulileyo ebeluncedo olungakanani na umnakekeli wakho</p>				
Alukho	 Alukho uncedo konke konke	 Uluncedo ngamanye amaxesha	 Uluncedo	 Uluncedo kahulu	
12.	<p>Ukususela kwiinyanga ezintandathu ezidlulileyo ebeluncedo kangakanani na umqeshi wakho</p>				
Alukho	 Alukho uncedo konke konke	 Uluncedo ngamanye amaxesha	 Uluncedo	 Uluncedo kahulu	
13.	<p>Ukususela kwiinyanga ezintandathu ezidlulileyo ingaba beziluncedo olungakanani na abanye oogogo ekukhuliseni abantwana babo abanokhubazeko</p>				
Alukho	 Alukho uncedo konke konke	 Uluncedo ngamanye amaxesha	 Uluncedo	 Uluncedo kahulu	
14.	<p>Ukususela kwiinyanga ezintandathu ezidlulileyo igaba bebeluncedo olunjani abanye oomhakhulu nootatomkhulu</p>				
Alukho	 Alukho uncedo konke konke	 Uluncedo ngamanye amaxesha	 Uluncedo	 Uluncedo kahulu	



















15.	Ukususela kwiinyanga ezintandathu ezidlulileyo bebeluncedo olungakanani na abanye oomhakhulu nootatomkhulu kwiindibano zenkxaso			
Alukho	 Alukho uncedo konke konke	 Uluncedo ngamanye amaxesha	 Uluncedo	 Uluncedo kahulu
16.	Ukususela kwiinyanga ezintandathu ezidlulileyo belungakanani na uncedo kubasenzi osebenza nabo			
Alukho	 Alukho uncedo konke konke	 Uluncedo ngamanye amaxesha	 Uluncedo	 Uluncedo kahulu
17.	Ukususela kwiinyanga ezintandathu ezidlulileyo ebeluncedo olungakanani na amanye amalungu eendibano zasekuhlaleni			
Alukho	 Alukho uncedo konke konke	 Uluncedo ngamanye amaxesha	 Uluncedo	 Uluncedo kahulu
(Empty row)				

18.	Ukususela kwiinyanga ezintandathu ezidlulieyo zibe ziluncedo kangakanani na amaqela eenkonzo okanye aiinkokheli ngokwasemoyeni			
Alukho	 Alukho uncedo konke konke	 Uluncedo ngamanye amaxesha	 Uluncedo	 Uluncedo kahulu
19.	Ukususela kwiinyanga ezintandathu ezidlulileyo ebeluncedo olunjani ugqirha wakho wekhaya okanye ugqirha womzukulwana wakho onokhubazeko			
Alukho	 Alukho uncedo konke konke	 Uluncedo ngamanye amaxesha	 Uluncedo	 Uluncedo kahulu
20.	Ukususela kwiinyanga ezintandathu ezidlulileyo ebeluncedo olunjani amaziko okunakekela umzukulwana wakho onokhubazeko			
Alukho	 Alukho uncedo konke konke	 Uluncedo ngamanye amaxesha	 Uluncedo	 Uluncedo kahulu

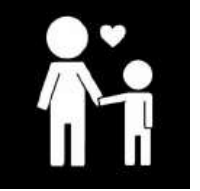





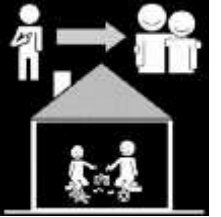





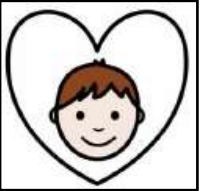





21.	Ukususela kwiinyanga ezintandathu ezidlulileyo bebeluncedo olungakanani na onontlalontle, abancedisi basekuhlaleni kwakunye nabanyangi			
Alukho	 Alukho uncedo konke konke	 Uluncedo ngamanye amaxesha	 Uluncedo	 Uluncedo kahulu
22.	Ukususela kwiinyanga ezintandathu ezidlulileyo bebeluncedo olunjani kumaziko ezakhono abongikazi, onontlalontle kwakunye nabanyangi bezengqondo			
Alukho	 Alukho uncedo konke konke	 Uluncedo ngamanye amaxesha	 Uluncedo	 Uluncedo kahulu
23.	Ingaba ngoobani abanye abantu okanye amanye amaqela ebeluncedo kwiinyanga ezintandathu ezidlulileyo? _____			



















**Appendix J3: Respondent's side of Booklet for Each Measure (Afrikaans)**


















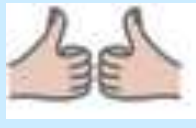
<b>PARENTAL STRESS SCALE</b>					
1.	U/Jy is gelukkig in u/jou rol as 'n versorger van u/jou gestremde kleinkind				
					
Stem ten sterkste nie saam nie	Stem nie saam nie	Onseker	Stem saam	Stem ten sterkste saam	
2.	U/jy sal doen wat u/jy ook al kan doen vir u/jou gestremde kleinkind				
					
Stem ten sterkste nie saam nie	Stem nie saam nie	Onseker	Stem saam	Stem ten sterkste saam	
3.	Die versorging van u/jou gestremde kleinkind neem soms meer tyd en energie as wat u/jy het om te gee				
					
Stem ten sterkste nie saam nie	Stem nie saam nie	Onseker	Stem saam	Stem ten sterkste saam	






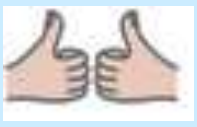





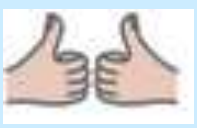





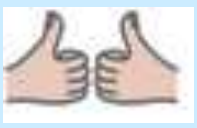
4.	Die grootmaak van u/jou gestremde kleinkind het beteken dat u/jy te min beheer oor u/jou lewe het				
 Stem ten sterkste nie saam nie		 Stem nie saam nie	 Onseker	 Stem saam	 Stem ten sterkste saam
5.	U/Jy wonder soms of u/jy genoeg doen vir u/jou gestremde kleinkind				
 Stem ten sterkste nie saam nie		 Stem nie saam nie	 Onseker	 Stem saam	 Stem ten sterkste saam
6.	Die gedrag van u/jou gestremde kleinkind is dikwels vir u/jou stresvol				
 Stem ten sterkste nie saam nie		 Stem nie saam nie	 Onseker	 Stem saam	 Stem ten sterkste saam
Empty row at the bottom of the table.					



















7.	U/Jy voel na aan u/jou gestremde kleinkind				
 Stem ten sterkste nie saam nie		 Stem nie saam nie	 Onseker	 Stem saam	 Stem ten sterkste saam
8.	U/Jy geniet dit om tyd saam met u/jou gestremde kleinkind deur te bring				
 Stem ten sterkste nie saam nie		 Stem nie saam nie	 Onseker	 Stem saam	 Stem ten sterkste saam
9.	U/Jou gestremde kleinkind is 'n belangrike bron van liefde vir u/jou				
 Stem ten sterkste nie saam nie		 Stem nie saam nie	 Onseker	 Stem saam	 Stem ten sterkste saam
(Empty row)					



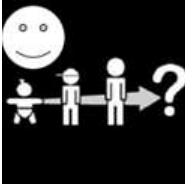

<p>10.</p>	<p>Die grootmaak van u/jou gestremde kleinkind bied aan u/jou 'n seker en meer positiewe siening van die toekoms</p>			
 <p>Stem ten sterkste nie saam nie</p>	 <p>Stem nie saam nie</p>	 <p>Onseker</p>	 <p>Stem saam</p>	 <p>Stem ten sterkste saam</p>
<p>11.</p>	<p>Die grootste bron van stres in u/jou lewe is u/jou gestremde kleinkind</p>			
 <p>Stem ten sterkste nie saam nie</p>	 <p>Stem nie saam nie</p>	 <p>Onseker</p>	 <p>Stem saam</p>	 <p>Stem ten sterkste saam</p>
<p>12.</p>	<p>Die grootmaak van u/jou gestremde kleinkind laat min tyd en buigsaamheid in u/jou lewe toe</p>			
 <p>Stem ten sterkste nie saam nie</p>	 <p>Stem nie saam nie</p>	 <p>Onseker</p>	 <p>Stem saam</p>	 <p>Stem ten sterkste saam</p>

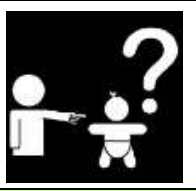
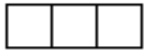

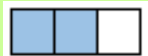





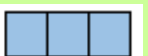
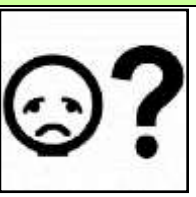



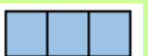


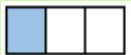


13.	Dit is 'n finansiële las om u/jou gestremde kleinkind groot te maak			
 Stem ten sterkste nie saam nie	 Stem nie saam nie	 Onseker	 Stem saam	 Stem ten sterkste saam
14.	Dit is moeilik om verskillende verantwoordelikhede te balanseer as gevolg van u/jou gestremde kleinkind			
 Stem ten sterkste nie saam nie	 Stem nie saam nie	 Onseker	 Stem saam	 Stem ten sterkste saam
15.	Die gedrag van u/jou gestremde kleinkind is dikwels vir u/jou 'n verleentheid			
 Stem ten sterkste nie saam nie	 Stem nie saam nie	 Onseker	 Stem saam	 Stem ten sterkste saam

<p>16.</p>	<p>As u/jy dit weer moes oordoen, sou u/jy dalk besluit het om nie u/jou gestremde kleinkind groot te maak nie</p>			
 <p>Stem ten sterkste nie saam nie</p>	 <p>Stem nie saam nie</p>	 <p>Onseker</p>	 <p>Stem saam</p>	 <p>Stem ten sterkste saam</p>
<p>17.</p>	<p>U/jy voel oorweldig deur die verantwoordelikheid daarvan om 'n ouer vir u/jou gestremde kleinkind te wees</p>			
 <p>Stem ten sterkste nie saam nie</p>	 <p>Stem nie saam nie</p>	 <p>Onseker</p>	 <p>Stem saam</p>	 <p>Stem ten sterkste saam</p>
<p>18.</p>	<p>Die grootmaak van u/jou gestremde kleinkind het beteken dat u/jy te min keuses in u/jou lewe het</p>			
 <p>Stem ten sterkste nie saam nie</p>	 <p>Stem nie saam nie</p>	 <p>Onseker</p>	 <p>Stem saam</p>	 <p>Stem ten sterkste saam</p>


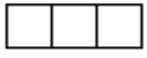




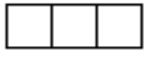









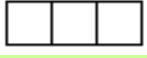



19.	U/Jy is tevrede as 'n grootouer				
 <p>Stem ten sterkste nie saam nie</p>		 <p>Stem nie saam nie</p>	 <p>Onseker</p>	 <p>Stem saam</p>	 <p>Stem ten sterkste saam</p>
20.	U/Jy geniet u/jou gestremde kleinkind				
 <p>Stem ten sterkste nie saam nie</p>		 <p>Stem nie saam nie</p>	 <p>Onseker</p>	 <p>Stem saam</p>	 <p>Stem ten sterkste saam</p>


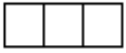









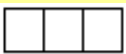
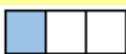


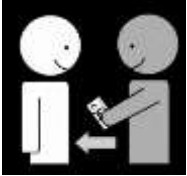
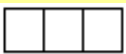
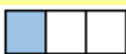


Personal Well-Being Index				
1.	Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy gevoel dat u/jy 'n baie goeie lewe het			
	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input checked="" type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/>	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/>
	U/jy het nog nooit so gevoel nie	U/jy het al af en toe so gevoel	U/jy het al soms so gevoel	U/jy het al dikwels so gevoel
2.	Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy vasgevang gevoel deur u/jou verantwoordelikhede as 'n versorger			
	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input checked="" type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/>	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/>
	U/jy het nog nooit so gevoel nie	U/jy het al af en toe so gevoel	U/jy het al soms so gevoel	U/jy het al dikwels so gevoel
3.	Sedert die begin van die maand/die afgelope twee weke, hoe dikwels was dit vir u/jou maklik om u/jou gestremde kleinkind fisies te versorg			
	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input checked="" type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/>	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/>
	U/jy het nog nooit so gevoel nie	U/jy het al af en toe so gevoel	U/jy het al soms so gevoel	U/jy het al dikwels so gevoel
4.	Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy nie lekker gevoel nie, of siek gevoel			
	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input checked="" type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/>	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/>
	U/jy het nog nooit so gevoel nie	U/jy het al af en toe so gevoel	U/jy het al soms so gevoel	U/jy het al dikwels so gevoel

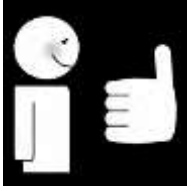
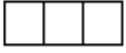


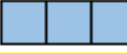
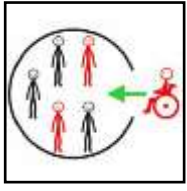
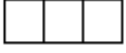


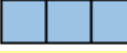

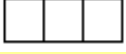




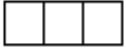



5.	Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy ongemaklik of bang gevoel sonder dat u/jy weet hoekom		
<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> U/jy het nog nooit so gevoel nie	<input checked="" type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> U/jy het al af en toe so gevoel	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/> U/jy het al soms so gevoel	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/> U/jy het al dikwels so gevoel
6.	Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy moeg of uitgeput gevoel nadat u/jy u/jou gestremde kleinkind versorg het		
<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> U/jy het nog nooit so gevoel nie	<input checked="" type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> U/jy het al af en toe so gevoel	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/> U/jy het al soms so gevoel	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/> U/jy het al dikwels so gevoel
7.	Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy gelukkig gevoel oor u/jou gestremde kleinkind se toekoms		
<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> U/jy het nog nooit so gevoel nie	<input checked="" type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> U/jy het al af en toe so gevoel	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/> U/jy het al soms so gevoel	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/> U/jy het al dikwels so gevoel
8.	Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy moeg of ooreis gevoel		
<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> U/jy het nog nooit so gevoel nie	<input checked="" type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> U/jy het al af en toe so gevoel	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/> U/jy het al soms so gevoel	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/> U/jy het al dikwels so gevoel


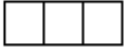


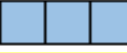

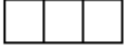




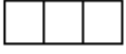




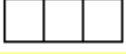


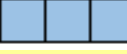
9.	Sedert die begin van die maand/die afgelope twee weke, hoe dikwels is daar vir u/jou geen einde aan die eise wat u/jou gestremde kleinkind aan u/jou stel nie		
 U/jy het nog nooit so gevoel nie	 U/jy het al af en toe so gevoel	 U/jy het al soms so gevoel	 U/jy het al dikwels so gevoel
10.	Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy baie energie gehad om dinge gedoen te kry (bv. huishoudelike take)		
 U/jy het nog nooit so gevoel nie	 U/jy het al af en toe so gevoel	 U/jy het al soms so gevoel	 U/jy het al dikwels so gevoel
11.	Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy terneergedruk of depressief gevoel		
 U/jy het nog nooit so gevoel nie	 U/jy het al af en toe so gevoel	 U/jy het al soms so gevoel	 U/jy het al dikwels so gevoel
12.	Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy baie energie gehad om by te hou by u/jou gestremde kleinkind		
 U/jy het nog nooit so gevoel nie	 U/jy het al af en toe so gevoel	 U/jy het al soms so gevoel	 U/jy het al dikwels so gevoel

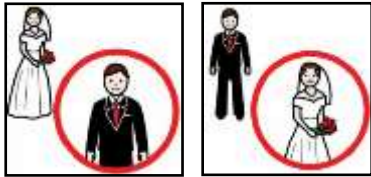
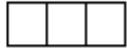

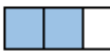
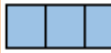

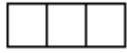

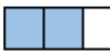
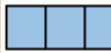

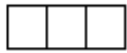
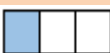
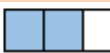
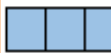



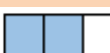
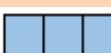



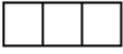




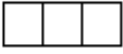




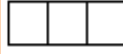





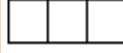


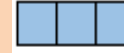
13.	Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy plesier gevind in die dinge wat u/jou gestremde kleinkind doen		
 U/jy het nog nooit so gevoel nie	 U/jy het al af en toe so gevoel	 U/jy het al soms so gevoel	 U/jy het al dikwels so gevoel
14.	Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy werklik gelukkig gevoel		
 U/jy het nog nooit so gevoel nie	 U/jy het al af en toe so gevoel	 U/jy het al soms so gevoel	 U/jy het al dikwels so gevoel
15.	Sedert die begin van die maand/die afgelope twee weke, hoe dikwels is dit 'n stremming vir u/jou om u/jou gestremde kleinkind te versorg		
 U/jy het nog nooit so gevoel nie	 U/jy het al af en toe so gevoel	 U/jy het al soms so gevoel	 U/jy het al dikwels so gevoel
16.	Sedert die begin van die maand/die afgelope twee weke, hoe dikwels het u/jy gevoel asof u/jy in 'n goeie fisiese toestand is		
 U/jy het nog nooit so gevoel nie	 U/jy het al af en toe so gevoel	 U/jy het al soms so gevoel	 U/jy het al dikwels so gevoel


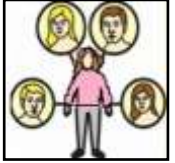

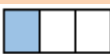
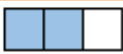



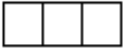





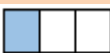
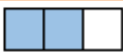


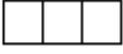



Support Functions Scale				
1.	Hoe dikwels benodig u/jy iemand waarmee u/jy kan praat oor dinge wat u/jou bekommer			
	 U/Jy benodig nooit hulp hiermee nie	 U/jy benodig af en toe hulp hiermee	 U/jy benodig soms hulp hiermee	 U/jy benodig baie dikwels hulp hiermee
2.	Hoe dikwels benodig u/jy iemand wat u/jou kan help met die versorging van u/jou gestremde kleinkind			
	 U/Jy benodig nooit hulp hiermee nie	 U/jy benodig af en toe hulp hiermee	 U/jy benodig soms hulp hiermee	 U/jy benodig baie dikwels hulp hiermee
3.	Hoe dikwels benodig u/jy iemand waarmee u/jy kan praat wanneer u/jy vrae het oor die grootmaak van u/jou gestremde kleinkind			
	 U/Jy benodig nooit hulp hiermee nie	 U/jy benodig af en toe hulp hiermee	 U/jy benodig soms hulp hiermee	 U/jy benodig baie dikwels hulp hiermee
4.	Hoe dikwels benodig u/jy iemand wat vir u/jou kan geld leen wanneer u/jy dit nodig het			
	 U/Jy benodig nooit hulp hiermee nie	 U/jy benodig af en toe hulp hiermee	 U/jy benodig soms hulp hiermee	 U/jy benodig baie dikwels hulp hiermee


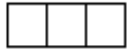




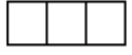




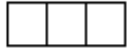






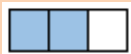




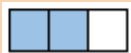

5.	Hoe dikwels benodig u/jy iemand om u/jou moed in te praat of u/jou te help om aan te gaan wanneer dit moeilik is			
 U/Jy benodig nooit hulp hiermee nie		 U/jy benodig af en toe hulp hiermee	 U/jy benodig soms hulp hiermee	 U/jy benodig baie dikwels hulp hiermee
6.	Hoe dikwels benodig u/jy iemand wat u/jou gestremde kleinkind aanvaar ten spyte van hoe hy of sy optree			
 U/Jy benodig nooit hulp hiermee nie		 U/jy benodig af en toe hulp hiermee	 U/jy benodig soms hulp hiermee	 U/jy benodig baie dikwels hulp hiermee
7.	Hoe dikwels benodig u/jy iemand om u/jou te help met huishoudelike take			
 U/Jy benodig nooit hulp hiermee nie		 U/jy benodig af en toe hulp hiermee	 U/jy benodig soms hulp hiermee	 U/jy benodig baie dikwels hulp hiermee
8.	Hoe dikwels benodig u/jy iemand saam met wie u/jy kan ontspaan of lag			
 U/Jy benodig nooit hulp hiermee nie		 U/jy benodig af en toe hulp hiermee	 U/jy benodig soms hulp hiermee	 U/jy benodig baie dikwels hulp hiermee

9.	Hoe dikwels benodig u/jy iemand wat dinge kan doen saam met u/jou gestremde kleinkind		
 U/Jy benodig nooit hulp hiermee nie	 U/jy benodig af en toe hulp hiermee	 U/jy benodig soms hulp hiermee	 U/jy benodig baie dikwels hulp hiermee
10.	Hoe dikwels benodig u/jy iemand wat vir u/jou of u/jou gestremde kleinkind kan help met vervoer		
 U/Jy benodig nooit hulp hiermee nie	 U/jy benodig af en toe hulp hiermee	 U/jy benodig soms hulp hiermee	 U/jy benodig baie dikwels hulp hiermee
11.	Hoe dikwels benodig u/jy iemand wat met SASSA (bv. toelae) of hospitaaldienste (bv. terapie of dokterafsprake) kan help wanneer u/jy nie kan nie		
 U/Jy benodig nooit hulp hiermee nie	 U/jy benodig af en toe hulp hiermee	 U/jy benodig soms hulp hiermee	 U/jy benodig baie dikwels hulp hiermee
12.	Hoe dikwels benodig u/jy iemand wat u/jou meer kan vertel oor dienste vir u/jou gestremde kleinkind of vir u/jou familie		
 U/Jy benodig nooit hulp hiermee nie	 U/jy benodig af en toe hulp hiermee	 U/jy benodig soms hulp hiermee	 U/jy benodig baie dikwels hulp hiermee


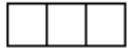
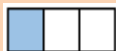



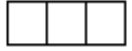
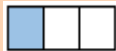


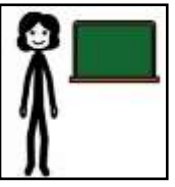
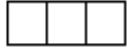
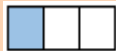



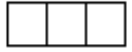



FAMILY SUPPORT SCALE					
1.	Gedurende die afgelope 6 maande, hoe behulpsaam was u/jou man/vrou of lewensmaat				
Nie beskikbaar nie	 Glad nie behulpsaam nie	 Soms behulpsaam	 Algemeen behulpsaam	 Uiters behulpsaam	
2.	Gedurende die afgelope 6 maande, hoe behulpsaam was u/jou ouer kind(ers)				
Nie beskikbaar nie	 Glad nie behulpsaam nie	 Soms behulpsaam	 Algemeen behulpsaam	 Uiters behulpsaam	
3.	Gedurende die afgelope 6 maande, hoe behulpsaam was u/jou bure				
Nie beskikbaar nie	 Glad nie behulpsaam nie	 Soms behulpsaam	 Algemeen behulpsaam	 Uiters behulpsaam	
4.	Gedurende die afgelope 6 maande, hoe behulpsaam was u/jou ouers				
Nie beskikbaar nie	 Glad nie behulpsaam nie	 Soms behulpsaam	 Algemeen behulpsaam	 Uiters behulpsaam	


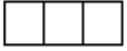



5.	Gedurende die afgelope 6 maande, hoe behulpsaam was u/jou ander kleinkinders				
Nie beskikbaar nie	 Glad nie behulpsaam nie	 Soms behulpsaam	 Algemeen behulpsaam	 Uiters behulpsaam	
6.	Gedurende die afgelope 6 maande, hoe behulpsaam was u/jou familie				
Nie beskikbaar nie	 Glad nie behulpsaam nie	 Soms behulpsaam	 Algemeen behulpsaam	 Uiters behulpsaam	
7.	Gedurende die afgelope 6 maande, hoe behulpsaam was u/jou vriende				
Nie beskikbaar nie	 Glad nie behulpsaam nie	 Soms behulpsaam	 Algemeen behulpsaam	 Uiters behulpsaam	
8.	Gedurende die afgelope 6 maande, hoe behulpsaam was die ouers van u/jou man/vrou of lewensmaat	 			
Nie beskikbaar nie	 Glad nie behulpsaam nie	 Soms behulpsaam	 Algemeen behulpsaam	 Uiters behulpsaam	

9.	Gedurende die afgelope 6 maande, hoe behulpsaam was die familie van u/jou man/vrou of lewensmaat				
Nie beskikbaar nie	 Glad nie behulpsaam nie	 Soms behulpsaam	 Algemeen behulpsaam	 Uiters behulpsaam	
10.	Gedurende die afgelope 6 maande, hoe behulpsaam was die vriende van u/jou man/vrou of lewensmaat				
Nie beskikbaar nie	 Glad nie behulpsaam nie	 Soms behulpsaam	 Algemeen behulpsaam	 Uiters behulpsaam	
11.	Gedurende die afgelope 6 maande, hoe behulpsaam was u/jou kinderoppasser				
Nie beskikbaar nie	 Glad nie behulpsaam nie	 Soms behulpsaam	 Algemeen behulpsaam	 Uiters behulpsaam	
12.	Gedurende die afgelope 6 maande, hoe behulpsaam was u/jou werkgewer				
Nie beskikbaar nie	 Glad nie behulpsaam nie	 Soms behulpsaam	 Algemeen behulpsaam	 Uiters behulpsaam	

13.	Gedurende die afgelope 6 maande, hoe behulpsaam was ander oupas en oumas wat hul gestremde kleinkind grootmaak				
Nie beskikbaar nie	 Glad nie behulpsaam nie	 Soms behulpsaam	 Algemeen behulpsaam	 Uiters behulpsaam	
14.	Gedurende die afgelope 6 maande, hoe behulpsaam was ander oupas en oumas				
Nie beskikbaar nie	 Glad nie behulpsaam nie	 Soms behulpsaam	 Algemeen behulpsaam	 Uiters behulpsaam	
15.	Gedurende die afgelope 6 maande, hoe behulpsaam was die lede van ondersteuningsgroepe vir oupas en oumas wat versorging doen				
Nie beskikbaar nie	 Glad nie behulpsaam nie	 Soms behulpsaam	 Algemeen behulpsaam	 Uiters behulpsaam	
16.	Gedurende die afgelope 6 maande, hoe behulpsaam was die mense wat saam met u/jou werk				
Nie beskikbaar nie	 Glad nie behulpsaam nie	 Soms behulpsaam	 Algemeen behulpsaam	 Uiters behulpsaam	
17.	Gedurende die afgelope 6 maande, hoe behulpsaam was die lede van u/jou sosiale groepe/klubs				
Nie beskikbaar nie	 Glad nie behulpsaam nie	 Soms behulpsaam	 Algemeen behulpsaam	 Uiters behulpsaam	



18.	Gedurende die afgelope 6 maande, hoe behulpsaam was die groeplede van u/jou geestelike groepe of u/jou geestelike leiers				
Nie beskikbaar nie	 Glad nie behulpsaam nie	 Soms behulpsaam	 Algemeen behulpsaam	 Uiters behulpsaam	
19.	Gedurende die afgelope 6 maande, hoe behulpsaam was u/jou gesinsdokter of die dokter van u gestremde kleinkind				
Nie beskikbaar nie	 Glad nie behulpsaam nie	 Soms behulpsaam	 Algemeen behulpsaam	 Uiters behulpsaam	
20.	Gedurende die afgelope 6 maande, hoe behulpsaam was die versorgingsentrums of dagsorg van u/jou gestremde kleinkind				
Nie beskikbaar nie	 Glad nie behulpsaam nie	 Soms behulpsaam	 Algemeen behulpsaam	 Uiters behulpsaam	
21.	Gedurende die afgelope 6 maande, hoe behulpsaam was professionele persone (bv. maatskaplike werkers, gemeenskapsrehabilitasiewerkers, terapeute)				
Nie beskikbaar nie	 Glad nie behulpsaam nie	 Soms behulpsaam	 Algemeen behulpsaam	 Uiters behulpsaam	

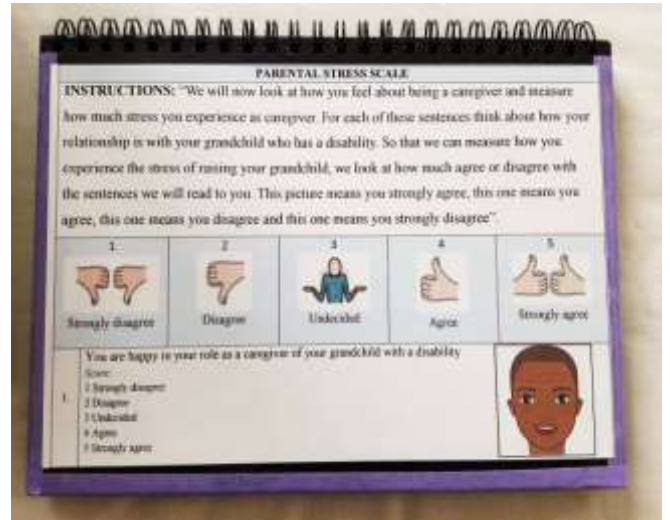
22.	Gedurende die afgelope 6 maande, hoe behulpsaam was professionele dienste (verpleegsters, maatskaplike dienste, geestelike gesondheid, ens.)			
Nie beskikbaar nie	 Glad nie behulpsaam nie	 Soms behulpsaam	 Algemeen behulpsaam	 Uitiers behulpsaam
23.	Wie is die ander mense of groepe wat oor die afgelope 6 maande vir u gehelp het?			

Appendix K: Response Booklets

12 Booklets of each measure in each of the three languages



Interviewer's side of first page containing instruction and first item



Participant's side








Interviewer's side first page



### Appendix L: Scoring Form and Scoring Criteria for PSS

Participant number \_\_\_\_\_ Date \_\_\_\_\_

#### Parental Stress Scale by Judy O. Berry & Warren H. Jones (1995)

		 <i>Strongly disagree</i>	 <i>Disagree</i>	 <i>Undecided</i>	 <i>Agree</i>	 <i>Strongly agree</i>
<b>S1 (R)</b>	You are happy in your role as a caregiver of your grandchild with a disability	1	2	3	4	5
<b>S2 (R)</b>	You would do everything you can for your grandchild with a disability	1	2	3	4	5
<b>S3</b>	Caring for your grandchild with a disability sometimes takes more time and energy than you have to give	1	2	3	4	5
<b>S4</b>	Raising your grandchild with a disability has meant having too little control over your own life	1	2	3	4	5
<b>S5</b>	You sometimes worry whether you are doing enough for your grandchild with a disability	1	2	3	4	5
<b>S6</b>	The behaviour of your grandchild with a disability is often stressful to you	1	2	3	4	5
<b>S7 (R)</b>	You feel close to your grandchild with a disability	1	2	3	4	5
<b>S8 (R)</b>	You enjoy spending time with your grandchild with a disability	1	2	3	4	5
<b>S9 (R)</b>	Your grandchild with a disability is an important source of love for you	1	2	3	4	5
<b>S10 (R)</b>	Raising your grandchild with a disability gives you a more certain and positive view for the future	1	2	3	4	5
<b>S11</b>	The major source of stress in your life is your grandchild with a disability	1	2	3	4	5
<b>S12</b>	Raising your grandchild with a disability leaves little time and flexibility in your life	1	2	3	4	5
<b>S13</b>	Raising your grandchild with a disability is a financial burden	1	2	3	4	5
<b>S14</b>	It is difficult to balance different responsibilities because of your grandchild with a disability	1	2	3	4	5
<b>S15</b>	The behaviour of your grandchild with a disability is often embarrassing to you	1	2	3	4	5
<b>S16</b>	If you had it to do over again, you might decide not to raise your grandchild with a disability	1	2	3	4	5
<b>S17</b>	You feel overwhelmed by the responsibility of being a caregiver to your grandchild with a disability	1	2	3	4	5
<b>S18</b>	Raising your grandchild with a disability has meant having too few choices	1	2	3	4	5
<b>S19 (R)</b>	You are satisfied as a grandparent	1	2	3	4	5
<b>S20 (R)</b>	You find your grandchild with a disability enjoyable	1	2	3	4	5

### SCORING OF PSS

To compute the parental stress score, **items 1, 2, 7, 8, 9, 10, 19, and 20** should be reverse scored as follows: **(1=5) (2=4) (3=3) (4=2) (5=1)**. The item scores are then summed.





Scoring the tool: We want a low score to signify a low level of stress, and a high score to signify a high level of stress. Overall possible scores on the scale range from 18 – 90. The higher the score, the higher the measured level of Parental stress.

<i>Category/subscale</i>		<i>Score</i>	
<b>Child Domain Subscale</b>			
<i>Demandingness of caregiving</i>	S3	Caring for grandchild takes more time and energy	
	S4	Too little control over your own life	
	S11	Grandchild is a major source of stress	
	S12	Little time and flexibility in life due to raising grandchild	
	S13	Raising grandchild is a financial burden	
	S16	Might never do it again	
	S18	Raising grandchild has meant having too few choices	
<i>Child behaviour</i>	S6	Grandchild's behaviour is stressful	
	S15	Behaviour of grandchild embarrassing	
	S20	Grandchild is enjoyable	____(R)____
<b>Parent Domain Subscale</b>			
<i>Sense of self competence</i>	S5	Worry whether for doing enough grandchild	
	S10	Positive view for the future when raising grandchild	____(R)____
	S14	Difficulty balancing different responsibilities because grandchild	
	S17	Overwhelmed by caregiver responsibility	
<i>Attachment to child</i>	S2	Do everything you can for grandchild	____(R)____
	S7	Feel close to grandchild	____(R)____
	S8	Enjoy spending time with grandchild	____(R)____
	S9	Grandchild as an important source of love	____(R)____
<i>Role conflict</i>	S1	Happy in role as a caregiver	____(R)____
	S19	You are satisfied as a grandparent	____(R)____
<b>TOTAL SUBSCALE SCORE</b>			

### Appendix M: Scoring Form and Scoring Criteria for PWBI

Participant number \_\_\_\_\_ Date \_\_\_\_\_

#### Personal Well-Being Index by Carol M. Trivette & Carl J. Dunst (1986)

		 You never felt like this	 You felt this once in a while	 You sometimes felt this	 You often felt this
<b>W1</b>	Since the beginning of the month/past 2 weeks how often have you felt that your life is going just great	1	2	3	4
<b>W2</b>	Since the beginning of the month/past 2 weeks how often have you felt trapped by your responsibilities as a caregiver of your grandchild with a disability	1	2	3	4
<b>W3</b>	Since the beginning of the month/past 2 weeks how often have you found it easy to physically take care of your grandchild with a disability	1	2	3	4
<b>W4</b>	Since the beginning of the month/past 2 weeks how often have you felt unwell or ill	1	2	3	4
<b>W5</b>	Since the beginning of the month/past 2 weeks how often have you felt uneasy or scared without knowing why	1	2	3	4
<b>W6</b>	Since the beginning of the month/past 2 weeks how often have you felt tired or exhausted after caring for your grandchild with a disability	1	2	3	4
<b>W7</b>	Since the beginning of the month/past 2 weeks how often have you felt glad about your grandchild with a disability's future	1	2	3	4
<b>W8</b>	Since the beginning of the month/past 2 weeks how often have you felt tired or run-down	1	2	3	4
<b>W9</b>	Since the beginning of the month/past 2 weeks how often have you seen no end to the demands your grandchild with a disability makes on you	1	2	3	4
<b>W10</b>	Since the beginning of the month/past 2 weeks how often have you had lots of energy to get things done (e.g. household chores)	1	2	3	4
<b>W11</b>	Since the beginning of the month/past 2 weeks how often have you felt down or depressed	1	2	3	4
<b>W12</b>	Since the beginning of the month/past 2 weeks how often have you had lots of energy to keep up with your grandchild with a disability	1	2	3	4
<b>W13</b>	Since the beginning of the month/past 2 weeks how often have you found pleasure in the things your grandchild with a disability does	1	2	3	4
<b>W14</b>	Since the beginning of the month/past 2 weeks how often have you felt really happy	1	2	3	4
<b>W15</b>	Since the beginning of the month/past 2 weeks how often have you found that caring for your grandchild with a disability puts a strain on you	1	2	3	4
<b>W16</b>	Since the beginning of the month/past 2 weeks how often have you been feeling like you are in great shape	1	2	3	4

### SCORING OF PWBI





- (A) Enter the individual items scores in the spaces provided.
  - (B) Sum the positive and negative items for each subscale.
  - (C) Add 8 to the positive sum, then subtract the negative sum from this to obtain the Total Subscale Score for each subscale.
  - (D) Sum the subscale score to obtain the Total Scale Score.
  - (E) If 2 or more items are missing, the subscale is not valid and should not be used.
- The sum of the ratings for all 16 items provides a global measure of well-being.

	<i>Category/subscale</i>	<i>Positive items</i>	<i>Negative items</i>	<i>Totals</i>
<b>I. General Emotional Subscale</b>				
W1	felt that your life is going just great		-----	
W5	felt uneasy or scared without knowing why	-----		
W11	felt down or depressed	-----		
W14	felt really happy		-----	
<b>TOTAL SUBSCALE SCORE</b>		8+____=____	-____	=____
<b>II. General Physical Subscale</b>				
W4	felt unwell or ill	-----		
W8	felt tired or run-down	-----		
W10	had energy to get things done (e.g. household chores)		-----	
W16	felt like you are in great shape		-----	
<b>TOTAL SUBSCALE SCORE</b>		8+____=____	-____	=____
<b>III. Child-Related Emotional Scale</b>				
W2	felt trapped by your responsibilities as a caregiver	-----		
W7	felt glad about your grandchild with a disability's future		-----	
W9	felt there is no end to the demands your grandchild with a disability makes on you	-----		
W13	found pleasure in the things your grandchild with a disability does		-----	
<b>TOTAL SUBSCALE SCORE</b>		8+____=____	-____	=____
<b>IV. Child-Related Physical Subscale</b>				
W3	felt it is easy to physically take care of your grandchild with a disability		-----	
W6	felt tired or exhausted after caring for your grandchild with a disability	-----		
W12	had energy to keep up with your grandchild with a disability		-----	
W15	felt like caring for your grandchild with a disability puts a strain on you	-----		
<b>TOTAL SUBSCALE SCORE</b>		8+____=____	-____	=____
<b>V.</b>	<b>TOTAL SCALE SCORE</b>			

### Appendix N: Scoring Form and Scoring Criteria for SFS

Participant number \_\_\_\_\_ Date \_\_\_\_\_

#### Support Functions Scale (short version) by *Carl J. Dunst & Carol M. Trivette (1986)*

		 You never need this help	 You need this help once in a while	 You sometimes need this help	 You need this help quite often
<b>F1</b>	How often do you feel you need someone to talk to about things that worry you	1	2	3	4
<b>F2</b>	How often do you feel you need someone to help take care of your grandchild with a disability	1	2	3	4
<b>F3</b>	How often do you feel you need someone to talk to when you have questions about raising your grandchild with a disability	1	2	3	4
<b>F4</b>	How often do you feel you need someone who can lend you money when you need it	1	2	3	4
<b>F5</b>	How often do you feel you need someone to encourage or keep you going when things seem hard	1	2	3	4
<b>F6</b>	How often do you feel you need someone who accepts your grandchild with a disability regardless of how he or she acts	1	2	3	4
<b>F7</b>	How often do you feel you need someone to help you with household chores	1	2	3	4
<b>F8</b>	How often do you feel you need someone with whom you can relax or laugh with	1	2	3	4
<b>F9</b>	How often do you feel you need someone to do things with your grandchild with a disability	1	2	3	4
<b>F10</b>	How often do you feel you need someone to help your grandchild with a disability or you with transportation	1	2	3	4
<b>F11</b>	How often do you feel you need someone to follow up with SASSA (e.g. grants) or hospital services (e.g. therapy/doctor appointments) when you can't	1	2	3	4
<b>F12</b>	How often do you feel you need someone who can tell you about services for your grandchild with a disability or your family	1	2	3	4



**SCORING OF SFS**

**Instructions:**





- A). Enter the individual item scores in the spaces provided.
- B). Sum the scores down each column to obtain the subscale scores.
- C). Sum **B.** subscale scores.
- D). Subtract **C.** from 60 to obtain **D.**  
Total Scale Score, so that higher scores indicate more support and less need for help.

<b>A. ITEM SCORES</b>		<b>Emotional support</b>	<b>Child support</b>	<b>Financial support</b>	<b>Instrumental support</b>	<b>Agency support</b>
F1	To talk to about things that worry you					
F2	To help take care of your grandchild with a disability					
F3	To talk to when you have questions about raising your grandchild with a disability					
F4	To lend you money when you need it					
F5	To encourage or keep you going when things seem hard					
F6	To accept your grandchild with a disability regardless of how he or she acts					
F7	To help you with household chores					
F8	To relax or laugh with					
F9	To do things with your grandchild with a disability					
F10	To help your grandchild with a disability or you with transportation					
F11	To follow up with SASSA (e.g. grants) or hospital services					
F12	To tell you about services for your grandchild with a disability or your family					
<b>B. SUBSCALE SCORES</b>		_____ + _____	_____ + _____	_____ + _____	_____ + _____	_____ + _____
<b>C. TOTAL SCALE SCORE=</b>						_____
<b>D. TOTAL SCALE SCORE</b>					60 - _____ = _____	

**Appendix O: Scoring Form and Scoring Criteria for FSS**

Participant number \_\_\_\_\_ Date \_\_\_\_\_

**Family Support Scale by *Dunst, Trivette, and Jenkins (1984)***

		Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful
<b>H1</b>	Since the past 6 months how helpful has <b>your husband/wife</b> or partner been	0	1	2	3	4
<b>H2</b>	Since the past 6 months how helpful have your older child(ren) been	0	1	2	3	4
<b>H3</b>	Since the past 6 months how helpful have your neighbours been	0	1	2	3	4
<b>H4</b>	Since the past 6 months how helpful have your parents been	0	1	2	3	4
<b>H5</b>	Since the past 6 months how helpful have your other grandchildren have been	0	1	2	3	4
<b>H6</b>	Since the past 6 months how helpful have your relatives been	0	1	2	3	4
<b>H7</b>	Since the past 6 months how helpful have your friends been	0	1	2	3	4
<b>H8</b>	Since the past 6 months how helpful have the <b>parents of your husband/wife</b> or partner been	0	1	2	3	4
<b>H9</b>	Since the past 6 months how helpful have the <b>relatives of your husband/wife</b> or partner been	0	1	2	3	4
<b>H10</b>	Since the past 6 months how helpful have the <b>friends of your husband/wife</b> or partner been	0	1	2	3	4
<b>H11</b>	Since the past 6 months how helpful has your nanny been	0	1	2	3	4
<b>H12</b>	Since the past 6 months how helpful has your employer been	0	1	2	3	4
<b>H13</b>	Since the past 6 months how helpful have other grandparents raising their grandchild with a disability been	0	1	2	3	4
<b>H14</b>	Since the past 6 months how helpful have other grandparents been	0	1	2	3	4
<b>H15</b>	Since the past 6 months how helpful have members of grandparent caregivers support group been	0	1	2	3	4
<b>H16</b>	Since the past 6 months how helpful have your co-workers been	0	1	2	3	4
<b>H17</b>	Since the past 6 months how helpful have members of your social groups/clubs been	0	1	2	3	4
<b>H18</b>	Since the past 6 months how helpful have your fellow religious group members or spiritual leaders been	0	1	2	3	4
<b>H19</b>	Since the past 6 months how helpful has your family doctor or the doctor of your grandchild with a disability been	0	1	2	3	4

<b>H20</b>	Since the past 6 months how helpful has your grandchild with a disability's care centres/crèche been	0	1	2	3	4
<b>H21</b>	Since the past 6 months how helpful have professional helpers (e.g. social worker, community rehab worker, therapists) been	0	1	2	3	4
<b>H22</b>	Since the past 6 months how helpful have professional services (nurses, social services, mental health etc.) been	0	1	2	3	4
<b>H23</b>	Who are the other people or groups who have been helpful for the past 6 months?					

### SCORING OF FSS

**Instructions:**













- A) Enter the individual item scores in the shaded spaces provided (i.e., the respondent’s rating [1, 2, 3, or 4]). Items rated NA are scored 0 (zero) for purposes of determining helpfulness scores.
- B) Sum the scores to obtain total subscale scores for the five major sources of support.
- C) Divide the subscale scores by the number of items per subcategory to obtain an average score (for comparative purposes).
- D) Sum the unadjusted scores for the four informal sources (kinship, spouse/partner, informal support & programs/organizations) of support subcategories to obtain the Informal Social Support Score.
- E) The unadjusted score for the professional services subcategory is the Formal Support Score.
- F) Sum the unadjusted scores for all 23 items to obtain the Total Family Support Scale Score.

<b>A. ITEM SCORES</b>		<i>Helpfulness of sources of support</i>				
		Kinship	Spouse/ Partner support	Informal support	Programs/ Organizations	Professional Services
H1	Husband/wife or partner					
H2	Older child(ren)					
H3	Neighbours					
H4	Parents (your)					
H5	Other grandchildren					
H6	Relatives (your)					
H7	Friends (your)					
H8	Husband/wife/partner’s parents					
H9	Husband/wife/partner’s relatives					
H10	Husband/wife/partner’s friends					
H11	Nanny					
H12	Employer					
H13	Other grandparents raising their grandchild with a disability					
H14	Other grandparents					
H15	Members of grandparent caregivers support group					
H16	Co-workers					
H17	Members of social groups/clubs					
H18	Fellow religious group members or spiritual leaders					
H19	Family doctor or the doctor of your grandchild with a disability					
H20	Grandchild with a disability’s care centres/crèche					
H21	Professional helpers					
H22	Professional services					
H23	Other					
<b>B. SUBSCALE SCORES (UNADJUSTED)</b>						
<b>C. ADJUSTED SOURCES OF SUPORT SCORES (AVERAGE)</b>						
<b>D. INFORMAL SUPPORT SCORE (SCORES FROM B)</b>		_____ + _____ + _____ + _____ = ____				
<b>E. FORMAL SUPPORT SCORE (SCORE FROM B)</b>						
<b>F. TOTAL SCALE SCORE (D+E)</b>					_____ + _____ = _____	

**Appendix P: Example of Community Resource Flyer**















**HELP & SUPPORT - UNCEDO KUNYE NENKXASO - HULP EN ONDERSTEUNING**

 <p><b>Emotional support for someone to talk to, if you are feeling depressed or if you have been a victim of violence</b>  <b>Inkxaso ngokwasemoyeni, xa uziva unoxinizelelo lwengqondo okanye ukhe wabandakanyeka kuhlukomezeko lobundlobongela</b>  <b>Emosionele ondersteuning vir iemand om mee te praat, indien jy depressief voel of as jy 'n slagoffer van geweld was</b></p>				
<p><b>Mental Health Information Line</b>   <b>Tel: 0800 21 22 23</b>                  (free)                  Mon-Sun: 08:00-20:00</p>	<p><b>HEAL (Halt Elder Abuse Line)</b>   <b>Tel: 0800 003 081</b>                  (free) (Anytime)</p>	<p><b>Trauma Clinic</b>    <b>Tel: 084 944 9444</b>                  (free) (Anytime)</p>	<p><b>Thuthuzela Care Centre at Khayelitsha Hospital</b>   <b>Tel: 021 360 4570/ 021 360 4704</b>                  (free) (Anytime)</p>	<p><b>Masibathande Seniors Project at Khayelitsha Centre on Wed, Thurs &amp; Fri</b>   <b>Tel: 073 247 8835</b></p>
<p> <b>Government Departments if you need to help from the government for information</b>  <b>Amaziho karulumente xa ufuna ulwazi malunga ngeenkonzo</b>  <b>Staatsdepartemente indien jy inligting of hulp van die regering benodig</b></p>				
<p><b>SASSA Office (Khayelitsha) to apply for grants/ inkonzo yezibonelelo ukufaka izicelo ngemali sibonelelo/ om vir toelae aansoek te doen</b>   <b>Tel: 021 3602100</b>                  Julius Ntsholo Street                  (near station)</p>	<p><b>Department of Social Development for social workers or safe house/ incandelo lezentllokahle ezimalunga nentlalontle oonontlalonte okanye iindawo zokhuseleko/ vir maatskaplike werkers of veiligheidshuise</b>   <b>Tel: 0800 220 250(free)</b>                  Mon - Fri: 07:00 - 19:00</p>	<p><b>Department of Social Development Substance Abuse Helpline for help with drugs and alcohol/ iinkonzo lezentllokahle icandelo loncedo ngeziyobisi eziqukaukusetyenziswa gwenxa kotywala iinombolo zokunceda / vir hulp met dwelms en alkohol</b>   <b>Tel: 0800 121 314(free)</b>                  (Anytime)</p>	<p><b>Department of Education Helpline for your grandchild's education/ icandelo lezemfundo malunga nomzukulwana wakho ngezemfundo/ vir jou kleinkind se opvoeding</b>   <b>Tel: 0800 202 933(free)</b>                  Mon - Fri: 08:00-16:00</p>	



**HELP & SUPPORT - UNCEDO KUNYE NENKXASO - HULP EN ONDERSTEUNING**

Emergency – Ngxakeko – Noodgeval				
<b>Hospital</b> Red Cross Children’s Hospital  Tel:  0861555 777 (free)	<b>Ambulance</b>   <b>Tel: 112 (free)</b>	<b>Fire Brigade</b>   <b>Tel: 107 (free)</b>	<b>Police</b>   <b>Tel: 10111 (free)</b>	<b>Missing Children South Africa</b>  <b>Tel: 072 647 7464</b> Mon – Sun (free) (Anytime)
 <b>Child Support for when you need help with caregiving</b> Iinkonzo zokunceda malunga nabantwana xa ufuna uncedo malunga nogcino nonakekelo lwabantwana Kinderondersteuning vir wanneer jy hulp benodig met versorging				
<b>Iris House</b> for when you need to go somewhere and you need someone to look after your grandchild for the day and if you need some time for yourself/ xa ufuna uncedo malunga neenkonzo zabo xa ufuna ukuya kupumla okanye uyokwenza iingxaki zako okanye ufuna umtu onokuti akupumze/ vir wanneer jy iewers heen moet gaan en jy iemand benodig om na jou kleinkind te kyk vir die dag en as jy tyd vir jousef nodig het  <b>Tel: 021 910 1578</b> Mon-Sun: 7.30am -5.30pm (Stikland Admin Old Paarl Road, Bellville)				
<b>Nobuntu Ngcoyi</b> to help you with your grandchild and to meet other grandparents who are also raising their grandchild with a disability/ ungaqhakamshela naye xa ufuna iingcebiso neenkonzo kwakunye neendibano nabanye oomhakhulu abakhulisa abazukulwana babo abanokubazeko/ om jou met jou kleinkind te help en om ander grootouers te ontmoet wat ook hul gestremde kleinkind grootmaak  <b>Tel: 0824567806</b> (Anytime)				

Compiled by Anushka Mantri-Langeveldt (PhD student at Centre for Augmentative and Alternative Communication, University of Pretoria) with acknowledgement of the University of Pretoria Research Support Bursary 2015-2016

## Appendix Q1: Procedural Script (English)

Steps followed	Instruction/question
1. Introduction of researcher and assistant	“Good morning/afternoon Ms/Mr. My name is _____ and this is _____, my assistant. Thank you very much for meeting with us today to participate in my study. I will be asking you some questions about the how stressed you have been and how you have been feeling and the supports you are using to raising your grandchild with a disability. It will take us about 45 min (to an hour) to do the interview and you can choose if you want it done in isiXhosa or Afrikaans or English. Which language do you prefer us to use for the interview?”
2. Receive consent of participant	“The information we get from you today will be kept confidentially and no one other than myself and my supervisor will have access to it and it will be kept safely at the University of Pretoria. Your name will not be mentioned anywhere in the study. To help me remember the information you are giving me I will have to record. If you agree with all of these, please sign here.”
<b>SECTION A</b>	
3. Complete biographical information and complete Ten Q form ( <i>switch on Olympus Voice recorder</i> )	“These questions give us information about you, and your grandchild(ren) who has a disability. For this study, your family is anyone who lives in the same household, who support and care for each other every day and who think of themselves as part of your family. They may or may not be related by blood.”
<b>SECTION B</b>	
4 i) Open the Parental Stress Scale booklet	“We will now look at how you feel about being a caregiver and measure how much stress you experience as caregiver. For each of these sentences think about how your relationship is with your grandchild who has a disability. So that we can measure how you experience the stress of raising your grandchild, we look at how much agree or disagree with the sentences we will read to you. This picture means you strongly agree, this one means you agree, this one means you disagree and this one means you strongly disagree”.
4 ii) Open the Personal Well-Being Index booklet	“Now we are going to look at your well-being, and we will try to measure how often it happens, like how often do you feel tired or how often do you feel happy. This ranges from ‘You never feel like this’ to ‘You often feel this’”. This picture means you ‘never feel like this’, this one means ‘you felt this once in a while’, this means that ‘you sometimes felt this’ and this one means ‘you often felt this’. Think about how you have felt since the beginning of the month/last two weeks when raising your grandchild with a disability”
4 iii) Open the Support Functions Scale booklet	“Now we will look at the types of support which you need and how often you need this help. To measure what types of supports you need, it varies from ‘You never need this help’ to ‘You need this help quite often’. This picture is for when you ‘never need this help’, this one is for when you ‘need this help once in a while’, this picture is for when you ‘sometimes need this help’ and this one is for when you ‘quite often need this help’.”
4 iv) Open the Family Support Scale booklet	“Now we will look at how helpful the people and groups are to you when raising your grandchild who has a disability. So that we can measure how helpful these different people and groups are to you, the pictures vary from “not at all helpful” to “extremely helpful”. If this person or group is not available to you, you can show this option (point to the not available option) and it means that the person or group is not there in your life. This picture means that the person or group is “not at all helpful”, this one means that they are “sometimes helpful” and this one means that they are “generally helpful” and this one means that they are “extremely helpful” to you. We want to look at how helpful these people or groups have been to you since the past six months (show visual timescale on calendar) when raising your grandchild with a disability.”
4 v) End the interview with community resource map and thanking of participant	“We have reached the end of the session. How do you feel the session went? Do you feel this was an eye-opener to your current situation? Raising a grandchild with a disability is not easy but it does not have to be a lonely process. I have a pamphlet here for you with contact details of various centres and people who can help you with support when you need it. But for them to help you, you have to let them know what you need help with so that the help can be more helpful to you. I wish to thank you again for your participation by offering you a small gift. Thank you for your valuable time. If you need any more information about this study, you can contact me on the number on the consent form.”

## Appendix Q2: Procedural Script (IsiXhosa)

Steps followed	Instruction/question
1. Introduction of researcher and assistant	“Molweni Mama u _____ lo ngumncedisi wam. Enkosi kakhulu ngokudibana nathi namhlanje ngenjongo zokuthatha inxaxheba kolu phando lwam. Olu phando lujonga indlela nina bomakhulu enithi nisebenzise ngayo inkxaso malunga nokukhulisa umzukulwana wakho okhubazekileyo kunye nefuthe loxinzelele othi ulufumane empilweni yakho. Olu dliwano ndlebe lizakuthatha imizuzu engamashumi amane anesihlanu yaye (1 hour) sizakulenza ngesixhosa okanye ngesibhulu okanye isingesi. Loluphi ulwimi ongathanda ukulisebenzisa koludliwano ndlebe?”
2. Receive consent of participant	“Ukuze sikwazi ukuqhubeka, ndicela uxele ukubangaba uyafuna na ukuthatha inxaxheba koluphando. Zonke inkcukaca esizothi sizifumane kuwe namhlanje zizokuziphatha ngemfihlelo kwaye akekho omnye umntu ngaphandle kwam ozokwazi ukuzifumana. Igama lakho alizukavela kulo lonke oluphando. Zonke inkcukacha esizothi zisifumane kuwe namhlanje zizokugcinwa ngokufihlakeleyo eDyunivesithi iminyaka elishumi elinesihlanu. Kwakhona, ukuze sikwazi ukuqondisisisa olu lwazisa uzosinika lona xasiluqokelela namhlanje, ndizocela ukuba silucishilele kwi video olu udliwano ndlebe. Ukubangaba uyavumelana nako konke oku, ndicela utyikitye apha kwezimpepha.”
<b>SECTION A</b>	
3. Complete biographical information and complete Ten Q form ( <i>switch on Olympus Voice recorder</i> )	“Le mibuzo ingolwazi ngawe, nomzukulwana okanye abazukulwana bakho abakhubazekileyo. Kolu phando, usapho lwakho nguye nabani nha ohlala edlini nawe, umntu enikhathaleleneyo mihla nemihla, nabazibona belusapho lwakho. Isenokwenzeka anizalani, okanye ayilogazi lakho.”
<b>SECTION B</b>	
4 i) Open the Parental Stress Scale booklet	“Siza kuthi sikhangele iimvakalelo zakho malunga nokuba ngumnakekeli sijonge uxinzelelo othi ujongane nalo kwakunye nolwazi lwako gabalala. Kula mabakala khawucingisise ubudlelane onabo nomzukulwana wakho onokhubazeko. Ngokwenza oku sakuti sibone indlela nolwazi gabalala noxinzelelo othi uhlangane nalo ekukhuliseni umzukulwana wako, siza kuthi sijonge ukuba sivumelana okanye asivumelani kangaka kwimibuzo esiza kuthi sikufundele yona. Lo mfanekiso ubonakalisa ukuba kungakanani na ukuvumelana kwako, okuthetha ukuba uyavuma na okanye awuvumelani kwaphela.”
4 ii) Open the Personal Well-Being Index booklet	“Ngokunje siza kuthi sijonge kuwe sizame nokuthi sibale iziganeko ezimalunga nokudinwa nokukhangela ukuba wonwabile na. Singajonga ngolu hlobo ndiziva ngoluhlobo lonke ixesha. Lo ngumfanekiso othetha ukuba awukazange wanemvakalelo ezi lo hlobo okanye abe khona amaxesha apo unemvakalelo ngolu hlobo kwaye yenzeka ngaxesha onke. Cinga ukuba ukhe wanemvakalelo ezi lolu hlobo ekuqalekeni kwenyanga/okanye kwiiveki ezimbini ukhulisa umzukulwana wakho onokhubazeko.”
4 iii) Open the Support Functions Scale booklet	“Ngokunje siza kujonga kwiintlobo ngeentlobo zenkxaso oyifunayo nekufumaniseke ukuba ingaluncedo kakhulu kuwe. Ukuqikelela inkxaso noncedo othe walufumana lukunceda kakhulu apho ke kunokwenzeka ukuba iyakunceda ngamanye amaxa okanye maxa onke. Lo mfanekiso ngowukuba awuzanga waludinga olu ncedo, lo ngowukuba wawukhe uludinge kanye ethubeni, lo umfanekiso ngowokuba ukhe uludinge oluncedo ngamaxa athile kwangokunjalo lo ngowokuba usoloko uludinga olu ncedo.”
4 iv) Open the Family Support Scale booklet	“Ngoku siza kukhe sijonge ukuba abantu namaqela baluncedo kangakanani na kuwe ekhukhuliseni umzukulwana wakho onokhubazeko. Ngokwenza oku singathi sibenokuqikelela ukuba abantu ngokohlukana kwabo kwakunye nemifanekiso eyahlukeneyo iyakunceda na ngokwaneleyo okanye ziluncedo kakhulu. Ukuba lo mntu okanye eli qela liyafumaneka kuwe ungakhetha kolu luhlu. Lo mfanekiso ithetha ukuba lomntu okanye eli qela liyabandakanyek. A kubomi bakho, lo mfanekiso ubonakalisa ukuba lo mntu okanye eli qela ayiluncedo kuwe konke konke, lo uthetha ukuthi ngamanye amaxesha babaluncedo kananjalo lo ubonakalisa ukuba baluncedo bekwaluncedo olukhulu kananjalo kuwe. Sifuna ukujonga ukuba ukuba aba bantu nala maqela baluncedo kangakanani na kuwe ukusukela kwiinyanga ezintandathu ezidluliyiyo (show visual timescale on calender) xa ukhulisa umzukulwana wakho onokubazeko.”
4 v) End the interview with community resource map and thanking of participant	“Sifikelele esiphelweni soviwondlebe. Ingaba ucinga olundliwano ndlebe belunjani okanye uziva njani? Ingaba ucinga ukuba oludliwanondlebe lukuvule amehlo koluxanduva ujongane nalo? Ukukhulisa umzukulwane okhubazekileyo akulula kodwa akunyanzelekanga ukuba



Steps followed	Instruction/question
	<p>umntu ojongane noluxanduva yedwa. Ndinencwadana apha ezinechukanca zamajelo nabantu abanokunika uncedo nobambiswano xa ukudinga oko. Kodwa ukuze bakwazi ukunceda kumele ubaxelele ukuba udinga bakuncede ngantoni ukuze uncedo lwabo lubeluncedo kuwe. Ndifuna ukukubulela kwakhona ngenxaxheba oyithathileyo ngokuthi ndikunike esisipho sincinci. Enkosi ngexesha lakho. Ukubangaba ufuna incazelo enzulu malunga noluphando, uze uncede undithinde incukacha zam zikhona kwi fomu yesivumelwano.”</p>

## Appendix Q3: Procedural Script (Afrikaans)

Steps followed	Instruction/question
1. Introduction of researcher and assistant	‘Goeiemôre/goeiemiddag Mnr/Me. Dit is Anushka en my naam is _____ en dis _____, my assistent _____. Baie dankie dat ons vandag met u kan praat en dankie vir u deelname aan my studie. Hierdie studie kyk na die manier waarop u as ’n grootouer sosiale ondersteuning gebruik om u gestremde kleinkind groot te maak en die studie kyk ook na hoe die spanning van versorging van die kind u welstand beïnvloed. Die sessie sal ongeveer 45 minute duur en ons sal die onderhoud in Xhosa of Afrikaans of Engels voer. Watter taal verkies u dat ons vir die onderhoud gebruik?’
2. Receive consent of participant	‘Voordat ons verder gaan, moet ek vra dat u sal sê of u aan die studie wil deelneem. Die inligting wat ons vandag van u kry, sal vertroulik hanteer word en niemand behalwe ek sal toegang daartoe hê nie. U naam sal nêrens in die studie enome word nie. Die inligting wat ons vandag van u ontvang, sal elektronies by die universiteit onder ’n wagwoord bewaar word vir 15 jaar. Verder, om my te help om sin te maak van die inligting wat ons vandag van u verkry, moet ek ’n video-opname van die sessie maak. As u met al die bogenoemde saamstem, onderteken asseblief die vorm.’
<b>SECTION A</b>	
3. Complete biographical information and complete Ten Q form ( <i>switch on Olympus Voice recorder</i> )	Hierdie vrae gaan oor inligting oor u en u gestremde kleinkind(ers). Vir hierdie studie is u familie enigiemand wat in dieselfde huishouding woon, wat elke dag mekaar ondersteun en vir mekaar omgee en wat hulself as deel van u familie beskou. Hierdie mense is nie noodwendig bloedverwante nie.
<b>SECTION B</b>	
4 i) Open the Parental Stress Scale booklet	“Ons sal nou kyk na hoe u/jy daarvoor voel om ’n versorger te wees en ons gaan meet hoeveel stres u/jy as versorger ervaar. Vir elkeen van die volgende sinne, dink oor u/jou verhouding met u/jou gestremde kleinkind. Om te meet hoeveel stres u/jy ervaar in die grootmaak van u/jou kleinkind, sal ons die sinne vir u/jou lees en luister tot watter mate u/jy daarmee saamstem of nie. Hierdie prentjie beteken u/jy stem ten sterkste saam, hierdie een beteken u/jy stem saam, hierdie een beteken u/jy stem nie saam nie en hierdie een beteken u/jy stem ten sterkste nie saam nie”.
4 ii) Open the Personal Well-Being Index booklet	“Ons gaan nou na u/jou welstand kyk en ons sal kyk na hoe u/jy dikwels voel, byvoorbeeld hoe dikwels u/jy moeg voel en hoe dikwels u/jy gelukkig voel. Dit wissel van ‘Ek voel nooit so nie’ tot ‘Ek voel altyd so’. Hierdie prentjie beteken u/jy voel nooit so nie, hierdie een beteken u/jy voel af en toe so, hierdie een beteken u/jy voel soms so en hierdie een beteken u/jy voel dikwels so. Dink oor hoe u/jy gevoel het sedert die begin van die maand/die afgelope twee weke.”
4 iii) Open the Support Functions Scale booklet	“Ons sal nou kyk na die tipes ondersteuning wat u/jy nodig het en wat vir u/jou waarde het. Om te kan meet watter ondersteuning u/jy nodig het en wat vir u/jou waarde het, sal ons kyk na hoe nodig u/jy hierdie soort hulp het. Dit wissel van ‘nooit’ na ‘dikwels’. Hierdie prentjie is beteken u/jy nooit hierdie hulp nodig het nie, hierdie een beteken u/jy dit af en toe benodig, hierdie prentjie beteken u/jy dit soms benodig, en hierdie een beteken u/jy dit dikwels nodig het.”
4 iv) Open the Family Support Scale booklet	“Nou gaan ons kyk na hoe behulpsaam die mense en groepe is wat u/jou help met die grootmaak van u/jou gestremde kleinkind. Om te kan meet hoeveel hierdie verskillende mense en groepe vir u/jou help, wissel die prentjies van nie beskikbaar tot uiters behulpsaam. Hierdie prentjie beteken dus dat die persoon of groep nie daar is in u/jou lewe nie, hierdie prentjie beteken dat die persoon of groep glad nie behulpsaam is nie, hierdie een beteken dat hulle soms behulpsaam is, en hierdie een beteken dat hulle uiters behulpsaam vir u is. Ons wil bepaal hoe behulpsaam hierdie mense of groepe gedurende die afgelope ses maande vir u/jou was (show visual timescale on calendar).”
4 v) End the interview with community resource map and thanking of participant	‘Ons is nou by die einde van die sessie. Hoe voel u hoe het dit met die sessie gegaan? Dink u dit het u oë oopgemaak vir u huidige situasie? Dit is nie maklik om ’n gestremde kleinkind groot te maak nie, maar dit hoef nie ’n eensame proses te wees nie. Ek het ’n pamflet hier vir u met kontakbesonderhede van verskeie sentrums en mense wat u kan ondersteun wanneer u dit nodig het. Maar hulle kan u slegs help as u vir hulle laat weet waarmee u hulp nodig het, sodat die hulp vir u meer behulpsaam kan wees. Ek wil u weer bedank vir u deelname deur vir u hierdie klein geskenkie te gee. Dankie vir u waardevolle tyd. As u nog inligting oor hierdie studie benodig, kan u my kontak op die nommer op die toestemmingsvorm.’

### Appendix R: Procedural Checklist

Stage of interview	Procedure	Yes	No
1. Introduction	Did researcher introduce herself and her assistant		
	Did the researcher give the participant a choice of the language to conduct the interview in		
	Was the purpose of the study stated and explained to the participant		
	Did the research indicate the length of time of the interview		
	Did the researcher explain how the interview process would proceed		
	Did the research explain that the interview would be recorded		
	Did the research assure confidentiality of the participant		
	Did the research explain that participation in the study was voluntary and withdrawal was also possible if needed		
2. Receipt of consent	Did the research provide the participant to ask questions about the research		
<b>SECTION A</b>			
3. Biographical information and Ten Questions Questionnaire form	Was the purpose of the biographical questionnaire and Ten Q form explained to the participant?		
	Did the researcher switch on the voice recorder		
	Were the questions of the biographical questionnaire and Ten Q read aloud to the participant		
	Did the researcher write in the answers of the participant		
<b>SECTION B</b>			
4. Booklets	Was process of the booklet explained to the participant		
i) Open the Parental Stress Scale booklet	Was the participant explained that they are required to point to the Likert scale as their response		
ii) Open the Personal Well-Being Index booklet	Did the researcher explain that the responses would be noted on the paper-based questionnaire		
	Was the participant given the opportunity to ask questions		
iii) Open the Support Functions Scale booklet	Did the researcher explain the visuals of the Likert scale responses to the participant		
	Before each item was read aloud, was the core concept of each graphic symbol explained to the participant		
iv) Open the Family Support Scale booklet	Did the assistant read aloud each item to the participant		
	Was the participant given enough time to respond and point		
v) End the interview with community resource mapping flyer	Did the researcher voice for the recorder the response of the participant		
	Did the assistant pause the interview if the participant became emotional		
	Did the researcher thank the participant for their input		
	Did the researcher explain the pamphlet of the community support available to the grandparent		

## Appendix S: Research Assistant and Procedural Raters Non-Disclosure Agreement



Faculty of Humanities

Date \_\_\_\_\_

I, \_\_\_\_\_ who is assisting Ms A.Mantri-Langeveldt in her study  
as a

Research Assistant

Procedural Rater

agree to preserve the confidentiality of the participants of this study by not divulging any  
identifiable information, such as their name, to other external parties.

Signature: \_\_\_\_\_

Signed at \_\_\_\_\_ Date \_\_\_\_\_

## Appendix T: Ethical Clearance Obtained from Ethics Committee of the Faculty of Humanities of the University of Pretoria



UNIVERSITEIT VAN PRETORIA  
UNIVERSITY OF PRETORIA  
YUNIBESITHI YA PRETORIA

Faculty of Humanities  
Research Ethics Committee

10 April 2018

Dear Ms Mantri

**Project:** Exploring caregiving stress, well-being and perceived social support for grandparents raising a grandchild with a congenital disability.  
**Researcher:** A Mantri  
**Supervisors:** Prof S Dada and Dr A Samuels  
**Department:** Augmentative and Alternative Communication  
**Reference number:** 29602590 (GW20150817HS)

Thank you for your response to the Committee's letter of 14 February 2018.

I have pleasure in informing you that the Research Ethics Committee formally **approved** the above study at an *ad hoc* meeting held on 3 April 2018. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should your actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

We wish you success with the project.

Sincerely

**Prof Maxi Schoeman**  
 Deputy Dean: Postgraduate and Research Ethics  
 Faculty of Humanities  
 UNIVERSITY OF PRETORIA  
 e-mail: tracey.andrew@up.ac.za

cc: Prof S Dada (Supervisor)  
 Dr S A Samuels (Co-Supervisor)  
 Prof J Bornman (HoD)

Research Ethics Committee Members: Prof MME Schoeman (Deputy Dean); Prof KL Harris; Dr L Dlalalind; Dr K Booyens; Dr A-M de Beer; Ms A dos Santos; Dr R Fasselt; Ms KT Govindar; Dr E Johanson; Dr W Kelleher; Mr A Mohamed; Dr C Puttergill; Dr D Reyburn; Dr M Saor; Prof E Taljard; Prof V Thebe; Ms B Tsebe; Ms D Mokalapa

## Appendix U: Letter to NGOs for Permission to Conduct Research, Examples of Questions and NGO Reply Slip



Faculty of Humanities

Date: \_\_\_\_\_

Name of Organisation:

Dear Mr. or Ms

My name is Anushka Mantri Langeveldt and I am a PhD student at the Centre for Augmentative and Alternative Communication, University of Pretoria. My study is entitled, *'Exploring caregiving stress, social support and well-being for grandparents raising a grandchild with a congenital disability'*.

The purpose of this research is to explore the experiences of caregiving stress, well-being as well as the sources and helpfulness of the social support which grandparents caregivers use when raising their grandchild with a disability. This study will contribute to better understanding the importance of encouraging the use of social support for grandparent caregivers who are raising their grandchild who has a disability. The specific type of grandparents I am looking to interview for my study are:

The grandparent caregiver has to be either the <b>primary caregiver</b> of the grandchild or a <b>co-parenting</b> (mother and/or father) living in the same household where the grandparent takes part in the many daily caregiving activities including parenting the grandchild.
---

The grandparent speaks either <b>English/ isiXhosa / Afrikaans</b>
--

The grandparent lives with and raises a grandchild who was <b>born with a disability Cerebral Palsy, Autism Spectrum Disorder, Foetal Alcohol Syndrome, Down Syndrome, deafness, visual impairment, global developmental delay and any other type of physical disabilities/impairment/disorder.</b>
---

The grandchild who was born with the disability is not more than <b>9 years old and is not in the formal school system.</b>
---

### What will the grandparent caregivers have to do?

The grandparents will be interviewed individually, by myself and a research assistant, during which a set of questionnaires will be completed. The completion of the questionnaires will be carried out verbally where the questions will be read aloud to the grandparent who will then be required to point to the picture on a scale that they represents how they feel about the question (*see attached example of questionnaires to be used*).

Participation in this research is **completely voluntary** and the participants will be made to understand that they may **withdraw** from the study if they feel they do not wish to continue with the study. At no point in time will the grandparents' names be used or any identifying information revealed. The grandparents will also be informed about their rights in

the study in either of the three languages they choose (*see attached example of grandparent invitation letter and consent form*).

The interview will consist of filling in questionnaires where each question will be read to the grandparent who will be required to point to the picture they most relate to. The interview is scheduled to take approximately **1 and half hour**. At the end of the interview some time will also be spent to provide the grandparent with some advice of where they can access the support they need in their community.

**How can your organisation assist with in this study?**

No costs will be incurred by either your organisation or the individual grandparents. I will be grateful if your organisation would allow me to contact and recruit potential participants and if possible, help me in identifying potential grandparents who you think could participate in my study. Furthermore, I would be grateful if a small space would be available for my assistant and me to conduct the interviews with the grandparents.

**Will you have access to the research results?**

I will share the results of this study with your organisation in a simple written format. Thank you for considering this request. Please inform me in writing of your decision and below on the **reply slip**, should your decision be favourable. Do not hesitate to contact me at the details below should you have any questions.

Yours Sincerely,

**Anushka Mantri Langeveldt**  
(Researcher)

**Professor Shakila Dada**  
(Supervisor)

---

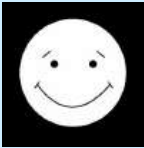





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Email [saak@up.ac.za](mailto:saak@up.ac.za)  
[www.caac.up.ac.za](http://www.caac.up.ac.za)






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Lefapha la Bomotheo









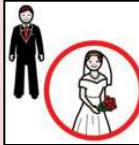




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**Examples of questions to be used:**

1. You are happy in your role as a parent/caregiver of your grandchild with a disability 				
 Strongly disagree	 Disagree	 Undecided	 Agree	 Strongly agree

1. Since the beginning of the month/past 2 weeks how often have you felt that your life is going just great 			
 You never felt like this	 You felt this once in a while	 You sometimes felt this	 You felt this quite often

1. How often do you feel you need someone to talk to about things that worry you 			
 <b>You never need this help</b>	 You need this help once in a while	 You sometimes need this help	 You often need this help

1. How helpful has your husband/wife or partner been  				
Not available	 Not at all helpful	 Sometimes helpful	 Generally helpful	 Extremely helpful

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**REPLY FORM: PERMISSION TO RECRUIT PARTICIPANTS**

To whom it may concern,

On behalf of \_\_\_\_\_ (name of organization), I am writing to formally indicate our awareness of the research proposed by Ms. Mantri-Langeveldt, a Ph.D. student at the University of Pretoria.

We are aware that she intends to conduct her research by means of questionnaires via interviews with grandparents raising their grandchild below the age of 9 years with a congenital disability.

I am also aware that the grandparent caregivers will be informed about all aspects of the study, specifically about their voluntary participation and the confidential treatment of all information.

I therefore grant her permission to conduct her research at our organization.

The number of children with a disability in our organization that are below the age of 9 years old and being raised by their grandparent are \_\_\_\_\_.

If you have any questions or concerns, please do not hesitate to contact me.

Sincerely,

Signature: \_\_\_\_\_

Name: \_\_\_\_\_

Date: \_\_\_\_\_



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**Appendix V1: Participant Invitation Letter and Consent Form (English)**



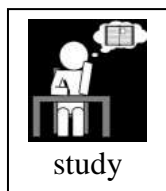
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**LETTER OF INVITATION TO GRANDPARENT FOR COMPLETION OF QUESTIONNAIRE**

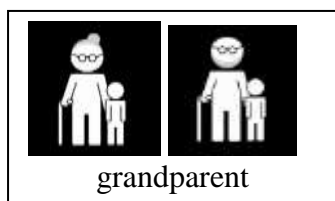
Date: \_\_\_\_\_

Dear Sir/Madam,

My name is Anushka Mantri Langeveldt and I am a PhD student at the Centre for Augmentative and Alternative Communication, University of Pretoria.



I am doing a study which is exploring the **social support** which you, as a



use when raising your grandchild who has a



**Benefits to you**

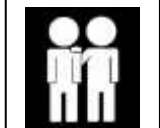
Although there may be no direct benefit to you, the potential benefit of your participation will be knowledge gained in understanding how grandparents are using social support to help them raise a grandchild with a congenital disability. This knowledge will help contribute to the much needed research about delivering early intervention services.


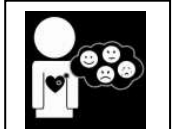
**Participants' rights**



Your participation in this research is **completely voluntary** and you can choose to  
at any time.




**What you will be doing?**


I will ask you some questions about you and your  family, who helps you and about how

they  help you. I will also ask you about how you  feel about raising your


grandchild with a  disability. We will be using  pictures to answer the questions.

Anytime during the interview, you can ask to stop if you need a break or if you feel tired. So

that I can remember all the information you give me today, I will have to  voice - record what we say in the interview. If you decide to not continue with the interview, you can tell me

to  and I will delete the voice recording and any information I have of you.

### Confidentiality

To protect your identity, your  name will **not** be used. The information I get today and the voice recording will only be seen by my supervisor and a research assistant. No one else will listen to the voice recording. When I have finished using the information in the voice recording, it will be securely stored for the purposes of research and archived for 15 years at the Centre for Augmentative and Alternative Communication, University of Pretoria.

## Research results

I will publish a thesis and an article on the results of the study and may also present the results at a conference. However, at no point will your name be mentioned in the publications, so nobody will know what you have shared with me.

If you have any more questions about the research study, please call me at [REDACTED] or e-mail me at [REDACTED].

Yours sincerely,

**Anushka Mantri Langeveldt  
(Researcher)**




**Associate Professor Shakila Dada  
(Supervisor)**









Faculty of Humanities



## CONSENT FORM FOR GRANDPARENT CAREGIVER

Do you understand that you have a  **CHOICE** to participate in this study?  **YES**   **NO**

Do you understand that I will  **VOICE - RECORD** during the interview?  **YES**   **NO**

Do you understand that you can  any time during the interview?  **YES**   **NO**

Do you understand that your  **NAME** will not be mentioned anywhere?  **YES**   **NO**

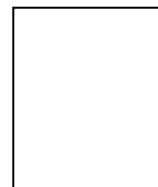
Do you want to take part in the study?  **YES**   **NO**



Name: \_\_\_\_\_ Participant's signature: \_\_\_\_\_

OR

Participant's



thumbprint:

Researcher: Anushka Mantri-Langeveldt

Researcher's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

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**Appendix V2: Participant Invitation Letter and Consent Form (IsiXhosa)**



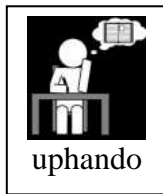
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**ILETA YOMEMO KOOTATAOMKHULU NOOMAKHULU  
UKUZE BATHATHE INXAXHEBA KWIMIBUZO**

Umhla: \_\_\_\_\_

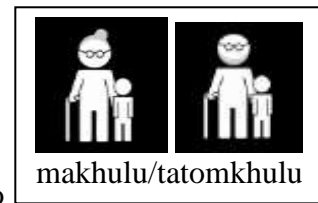
Nene/nenekazi

Igama lam ngu-Anushka Mantri Langeveldt ndingumfundi we-PhD e-Centre for Augmentative and Alternative Communication, KwiDyunivesiti yasePetoli.



Ndenza

olujonga uncedo lwentlalo apho wena njengo



olusebenzisayo wena ukukhulisa umzukulwana wakho

**Yintoni wena ozakuyizuza koluphando**

Nangona ungazolubona uzuzo kwangoku, kodwa ukuthatha kwakho inxaxheba ingalulwazi olunonceda ekuqondeni ukuba oomakhulu/tatomkhulu balusebenzisa njani uncedo lwentlalo ukunceda ukukhulisa abazukulwana abakhubazelikeyo. Olulwazi lunganceda kuphando oludingekayo ngokunceda ukuphuhlisa uncedo olukhawulezisileyo kwezi meko.

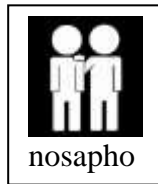
**Amalungelo omthathi nxaxheba**

Ukuthatha kwakho inxaxheba koluphando kuxomekeke kuwe kwayo kukuzikhethela komntu

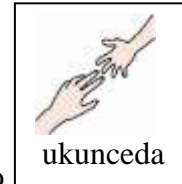


ungakhetha nanini uthanda.

**Uzobe usenza ntoni?**

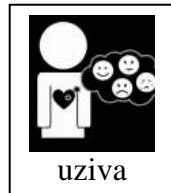


nosapho



ukunceda

Ndizokubuza imibuzo ngawe lwakho, ngubani okuncedayo njani.



uziva

Ndizakubuza ukuba wena njani ngokukhulisa umzukulwana wakho

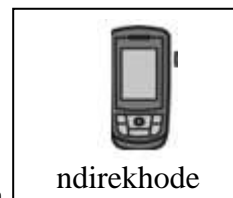


okhubazekileyo



imifanekiso

Sizokusebenzisa ukuphendula imibuzo. Nanini nha koludliwanondlebe, ungacela uyeka ukuba ufuna ukuphumla okanye udiniwe. Ukuze



ndirekhode

ndikhumbule yonke into ondixelela yona namhlanje, kuzofuneka lento uyithethayo kudliwanondlebe. Ukuba uyeukhetha ukuyeka oludliwanondlebe, ungandixelela



ukuba mandiyekel ndiyakudeletha yonke into ekwirekhoda nalolonke ulwazi endinalo ngawe.

**Imfihlo ngolwazi?**

Ukukhusela wena, alizosetyenziswa. Ulwazi endilufumana namhlanje nendikurekhodileyo luzokubonwa yisuphaviyiza yam nomntu ondancedisa ngophando kuphela. Akekho omnye umntu ozakumamela irekhoda. Xa ndiqibile ukusebenzisa ulwazi olu lukwirekhoda, iyokufakwa kwindawo ekhuselekileyo ukunceda koluphando lugcinwe iminyaka eyi-15 kwi-Centre for Augmentative and Alternative Communication, kwiDyunivesiti yasePitoli.

**Ulwazi oluqokelelweyo**

Ndizokubhala iphepha ngolulwazi ndiluqokeleleyo, nephepha apho ndiyoku thetha ngezinto endizifumeneyo kwikhonfrensi. Kodwa akukho apho ndiyokucaza igama lakho, xa ndikhupha iphepha, kunjalo nje akukho namnye umntu ozakuyazi into ondixelele yona.

IUkuba unayo eminye imibuzo ngoluohando, cela uzame ukundifowanela ku- [REDACTED] orkanye undi-e-mail ku- [REDACTED].

Ozithobileyo,

**Anushka Mantri Langeveldt  
(Umphandi)**


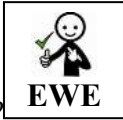

**Professor Shakila Dada  
(Isuphavayiza)**








Faculty of Humanities



## IFOMU YOKUVUMA

Uyaqonda ukuba  **UNGAKHETHA** ukuthatha inxaxheba koluphando?   

Uyaqonda ukuba kuzosetyenziswas  **UMSHINI WOREK HODA** kolundliwano ndlebe?   

Uyaqonda ukuba uyakwazi ukuba ungathi  nanini nha koludliwano ndlebe?   

Uyaqonda ukuba  **IGAMA** lakho alizosetyenziswa nanini nha?   

Uyafuna ukuthatha inxaxheba koludliwanondlebe?   



**Igama:** \_\_\_\_\_ **Utyikityo lomthathi nxaxheba** \_\_\_\_\_  
**Okanye**

**Umphandi:** Anushka Mantri-Langeveldt

**Utyikityo lomphandi:** \_\_\_\_\_

**Umhla:** \_\_\_\_\_

**Ubontsi:**

Centre for Augmentative and Alternative  
Communication, Room 2-36, Com path  
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University of Pretoria, Private Bag X20  
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Lefapha la Bomothe

### Appendix V3: Participant Invitation Letter and Consent Form (Afrikaans)



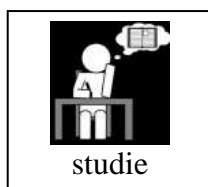
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#### UITNODIGINGSBRIEF AAN GROOTOUER VIR VOLTOOIING VAN VRAELYS

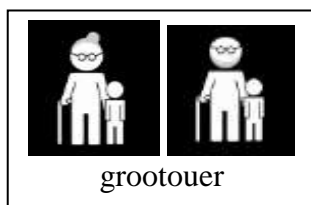
Datum: \_\_\_\_\_

Beste Meneer of Mevrouw,

My naam is Anushka Mantri Langeveldt en ek is 'n PhD-student by die Sentrum vir Aanvullende- en Alternatiewe Kommunikasie by die Universiteit van Pretoria.



Ek werk aan 'n wat ondersoek instel na die **sosiale ondersteuning** wat u as



'n gebruik terwyl u u



grootmaak.

#### Voordele vir u

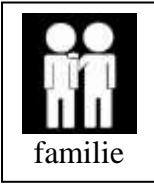

Alhoewel daar geen direkte voordeel vir u mag wees nie, is die potensiële voordeel van u deelname dat ons meer kennis kan kry ten opsigte van hoe grootouers sosiale ondersteuning gebruik om hulle te help in die grootmaak van 'n kleinkind met 'n aangebore gestremdheid. Hierdie kennis sal bydra tot navorsing wat ons baie nodig het in die lewering van vroeë ingrypingsdienste.

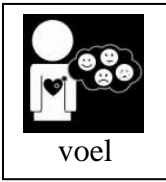

## Deelnemers se regte


U deelname aan hierdie navorsing is **ten volle vrywillig** en u kan op enige tyd deelname





## Wat u moet doen?

Ek gaan vir u vrae vra oor u en u  familie, die mense wat u  help en oor hoe hulle

u help. Ek sal u ook vra oor hoe u  voel daaroor om u  gestremde kleinkind groot te maak.


Ons sal  prente gebruik om die vrae te beantwoord. U kan op enige tyd gedurende die onderhoud vra om te stop as u 'n ruskans nodig het of as u moeg voel. Omdat ek al die inligting

wil onthou wat u vandag vir my gee, sal ek 'n  stem opnam van die onderhoud maak. As u besluit

dat u nie met die onderhoud wil voortgaan nie, kan u vir my vra om te  en ek sal die stem opname en enige inligting wat ek van u het, uitwis.



## Vertroulikheid



Om u identiteit te beskerm, sal u  nie gebruik word nie. Die inligting wat ek vandag kry en die stem opname, sal slegs deur my toesighouer en 'n navorsingsassistent geluister word. Niemand anders sal na die stem opname luister nie. Wanneer ek klaar die stem opname en u inligting gebruik het, sal dit vir navorsingsdoeleindes vir 15 jaar veilig bewaar word in die argief by die Sentrum vir Aanvullende- en Alternatiewe Kommunikasie by die Universiteit van Pretoria.

## Navorsingsresultate

Ek gaan 'n tesis en 'n artikel skryf oor die uitslae van die studie en dit kan moontlik ook by 'n konferensie aangebied word. U naam sal egter op geen stadium in die publikasies genoem word nie en niemand sal dus weet wat u met my gedeel het nie.

Indien u enige vrae oor hierdie navorsingstudie het, skakel my asseblief by  of stuur 'n e-pos na .

Vriendelike groete,


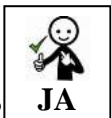

**Anushka Mantri Langeveldt**  
(Navorsers)

**Professor Shakila Dada**  
(Supervisor)






Faculty of Humanities




**TOESTEMMINGSVORM VIR GROOTOUER-VERSORGER**


**KEUSE**

**JA** 

**NEE**

Verstaan u dat u 'n **KEUSE** het om aan hierdie studie deel te neem?


**STEM-OPNAME**

**JA** 

**NEE**

Verstaan u dat ek 'n **STEM-OPNAME** van hierdie onderhoud gaan maak?


**NAAM**

**JA** 

**NEE**



Verstaan u dat u naam **NAAM** nêrens genoem sal word nie?



**JA** 

**NEE**

Verstaan u dat u op enige tydstep hierdie onderhoud kan laat **STOP**?


**JA** 

**NEE**

Wil u aan die studie deelneem?



**Naam:** \_\_\_\_\_ **Handtekening:** \_\_\_\_\_

OF

**Vingerafdruk**



**Navorsers:** Anushka Mantri Langeveldt

**Handtekening:** \_\_\_\_\_ **Datum:** \_\_\_\_\_

## Appendix W1: Easy-to-read pamphlet of study (English)

Exploring the relationship between perceived social support, caregiving stress and well-being of grandparents raising a grandchild with a congenital disability

by Anushka Mantri-Langeveldt (PhD student) [anushkamantri@gmail.com](mailto:anushkamantri@gmail.com)

Supervised by Prof. Shakila Dada [shakila.dada@up.ac.za](mailto:shakila.dada@up.ac.za) and

Dr. Alecia Samuels [alecia.samuels@up.ac.za](mailto:alecia.samuels@up.ac.za)



Centre for Augmentative and Alternative Communication, University of Pretoria



UNIVERSITEIT VAN PRETORIA  
UNIVERSITY OF PRETORIA  
YUNIBESITHI YA PRETORIA

### WHY WE DID THIS STUDY:

Around the world, grandparents are important. They are helping parents to raise their grandchild  or they raise their grandchild alone if the parent cannot do so.

Raising a grandchild with a  disability can be stressful . But there are few studies which tell us about grandparents who raise

### WHAT WE WANTED TO KNOW:

We wanted to know how much stress do grandparents feel. How much emotional and physical well-being do they have?



; What kind of social supports do they need? ; How do social support, stress and well-being relate to each other?











### WHO PARTICIPATED:

We interviewed 50 grandparents in their home or at the NGOs. The grandparents spoke IsiXhosa, Afrikaans and English.



### WHAT WE FOUND:

We found that grandparents when raising their grandchild with a disability were:

- ◆ Stressed  because of the increased time and energy and financial difficulties ◆ Not feeling well and healthy 
- ◆ They need encouragement  ◆ They need someone to talk to when they are worried 
- ◆ They love and enjoy their grandchild  ◆ The more  stress the grandparents had, the lower was their  well-being
- ◆ The more  social support they had, the lower was their  stress and better  was their well-being.

### WHAT CAN HELP YOU AS A GRANDPARENT WHEN RAISING YOUR GRANDCHILD:

- ✓ Find people and organisations that can help you
- ✓ Tell the people and organisations what you need so that they can support you better
- ✓ Attend support groups so that you can meet other grandparents who are also raising their grandchild who has a disability
- ✓ Ask your grandchild's doctor or therapist for more information about your grandchild's disability



ACKNOWLEDGMENTS: Thank you to all the grandparents and the NGOs

**Appendix W2: Easy-to-read pamphlet of study (IsiXhosa)**

Exploring the relationship between perceived social support, caregiving stress and well-being of grandparents raising a grandchild with a congenital disability

by Anushka Mantri-Langeveldt (PhD student) [anushkamantri@gmail.com](mailto:anushkamantri@gmail.com)

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**BEKUTHENI UKUZE SENZE ESISIFUNDO:**

Elizweni jikelele, oomakhulu nootatomkhulu bablulekile. Bancedisa ukukhulisa abazukulwana babo okanye bakhulise abazukulwana babo bodwa ukuba abazali abakwazi. Ukukhulisa umzukulwana o-khubazekileyo ingayinto leyo esisicinezelo . Kodwa zikhona izifundo ezisixelelayo ngoomakhulu nootatomkhulu abakhulisa abazukulwana abakhubazekileyo.

**YINTONI EBESIFUNA UKUYAZI:**

Sifuna ukwazi ukuba baziva becinezeleke kangakanani oomakhulu nootatomkhulu. Ngokusemphefumleni nangokwenyama banakekelwe kangakanani? ; Badinga inxaso enjani ngokwasekuhlaleni? ; Inxaso ngokwasekuhlaleni ukudandatheka nangendlela ophila ngayo zinxulumene njani ezozinto enye kwenye kuwe?

**NGUBANI OTHATHE INXAXEBA:**

Senze udliwano ndlebe nootatomkhulu noomakhulu abayi-50 kwizindlu zabo okanye kwiNGO. Oomakhulu nootatomkhulu bebethetha isiXhosa, isiBhulu okanye isiNgesi.



**SIFUMANISE NTONI:**

Sifumanise ukuba oomakhulu okanye ootatomkhulu abakhulisa abazukulwana abakhubazekileyo baya:

- ◆ Dandatheka ngokuba ixesha elinintsi namandla amanintsi nobunziba ngokwezimali ◆ Abaphilanga kwaye abazivibesempilweni ◆ Badinga ukukhuthazwa ◆ Badinga umntu wokuthetha xa benexhala ◆ Bayabathanda kwaye bayabonwabela abazukulwana babo ◆ Xa bedandatheka empilweni zabothe, thekukhwehla kwezinga lobomi babo ◆ Xa kongezeleka inxaso ngokwasekuhlaleni, bekufumaniseka liyehla izinga lokudandatheka kubengcono ngokwempilo yabo.

**YINTONI ENONINCELA NJENGOOMAKHULU NOOTATOMKHULU XA NIKHULISA ABAZUKULWANA:**

- ✓ Fumana abantu okanye indawo enokunceda
- ✓ Xelela abantu okanye indawo ukuba udinga ntoni ukuze bakwazi ukuxhasa
- ✓ Hamba indawo ezinamaqela okuxhasa ukuze ukwazi ukudibana nabanye oomakhulu okanye ootatomkhulu abakunisa abazukulwana abakhubazekileyo
- ✓ Cela ugqirha womzukulwana wakho okanye ingcali yokunyanga umzukulwana wakho ngolwazi oluthe vetshe ngokukhubazeka komzukulwana wakho



**IZAZISO: Ukubulela bonke oomakhulu nootatomkhulu kunye neeNGO**



### Appendix W3: Easy-to-read pamphlet of study (Afrikaans)

Exploring the relationship between perceived social support, caregiving stress and well-being of grandparents raising a grandchild with a congenital disability

by Anushka Mantri-Langeveldt (PhD student) [anushkamantri@gmail.com](mailto:anushkamantri@gmail.com)


Supervised by Prof. Shakila Dada [shakila.dada@up.ac.za](mailto:shakila.dada@up.ac.za) and



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#### WAAROM ONS HIERDIE STUDIE GEDOEN HET:


Oupas en Oumas is oral in die wêreld belangrik. Hulle help ouers om hul kleinkinders groot te maak  of hulle maak hul kleinkinders alleen groot as die ouers dit nie kan doen nie.

Om 'n gestremde kleinkind groot te maak  kan stresvol wees . Maar daar is nie veel studies wat vertel van grootouers wat 'n gestremde kleinkind grootmaak nie.

#### WAT ONS WOU WEET:

Ons wou weet hoeveel stres grootouers ervaar. Hoe goed is hul emosionele en fisiese welstand? ; Watter tipe sosiale ondersteuning het hulle nodig? ; Wat het sosiale ondersteuning, stres en welstand met mekaar te doen?

#### WIE HET DEELGENEEM:

Ons het met 50 grootouers by hul huise of by die nie-regeringsorganisasies onderhoude gevoer. Die grootouers het IsiXhosa, Afrikaans en Engels gepraat. 

#### WAT ONS BEVIND HET:

Ons het bevind dat grootouers wat 'n gestremde kleinkind grootmaak:

◆ Stres ervaar  omdat hulle min tyd en energie gehad het en finansiële probleme gehad het en dat hulle ◆ Nie gesond gevoel het nie  ◆ Hulle het aanmoediging nodig  ◆ Hulle het iemand nodig om mee te praat wanneer hulle bekommerd is  ◆ Hulle is lief vir hul kleinkind en geniet hom/haar  ◆ Hoe meer stres die grootouers ervaar het, ↑ hoe laer was hul ↓ welstand ◆ Hoe meer ↑ sosiale ondersteuning hulle gehad het, hoe laer ↓ was hul stresvlakke en hoe beter ↑ was hul welstand.

#### WAT KAN JOU AS GROOTOUER HELP OM JOU KLEINKIND GROOT TE MAAK:

- ✓ Soek mense en organisasies wat jou kan help.
- ✓ Vertel vir die mense en organisasies wat jy nodig het sodat hulle jou beter kan ondersteun.
- ✓ Woon ondersteuningsgroepe by sodat jy ander grootouers kan ontmoet wat ook hul gestremde kleinkind grootmaak.
- ✓ Vra jou kleinkind se dokter of terapeut vir meer inligting oor jou kleinkind se gestremdheid.



ERKENNINGS: Dankie aan al die grootouers en NRO's.