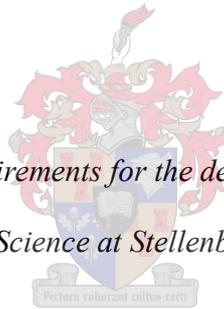


**Experiences of Caregivers of Children with Disabilities  
in Semi-Rural Areas Near Cape Town, South Africa**

by

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*Thesis presented in fulfilment of the requirements for the degree of Master of Science (Psychology) in  
the Faculty of Science at Stellenbosch University*



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## Declaration

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### Abstract

In South Africa, despite government policies aimed at supporting caregivers of children with disabilities, some caregivers still experience challenges and receive little support. In collaboration with the Disabled Children's Action Group (DICAG), I investigated the experiences of 23 caregivers of children with disabilities—including parents, siblings, and care centre employees—at DICAG-affiliated centres near Cape Town, South Africa. With an interpreter, I conducted in-depth semi-structured interviews with caregivers in English, Afrikaans, and/or isiXhosa to explore their experiences. After interview transcription and translation into English, I analysed the data using thematic analysis followed by Tronto's (1993) conceptualisation of care, comprising four stages of practice and associated virtues. I present findings about participants' experiences using Tronto's (1993) framework, illustrating participants' stories relating to caring about and being attentive, taking care and being responsible, caregiving and being competent, and care receiving and responsiveness to children with disabilities. Using an ethics of care theoretical framework, I highlight the importance of learning from caregivers' experiences in order to find ways of creating a more caring society, in which the needs of both caregivers and the cared for—children with disabilities in this case—are attended to and met, and in which care work is more equitably distributed. After discussing limitations of the study, I compare the findings with existing South African literature and care ethics, and suggest implications for research, service, and activism.

*Keywords:* Caregivers, Parents, Mothers, Fathers, Siblings, Disability, Chronic Illness, Child care, Ethics of care, South Africa

### Opsomming

Ten spyte van die Suid- Afrikaanse regering se beleide gerig daarop om versorgers van kinders met gestremdhede te ondersteun, ontvang sommige versorgers selde ondersteuning en ervaar hulle steeds uitdagings. In samewerking met die *Disabled Childrens' s Action Group* (DICAG), ondersoek ek die ervaringe van 23 versorgers van kinders met gestremdhede – insluitend die ouers, familieledede en personeel van die versorgings sentrum- by DICAG erkende sentrums naby Kaapstad, Suid- Afrika. Ter ontdekking van hul ondervindinge het ek te same met 'n tolk, in-dipete semi-struktureerde onderhoude gevoer met versorgers in Engels, Afrikaans, en/of isiXhosa. Na onderhoude getranskribeer en vertaal is na Engels, is die data geanaliseer deur van tematiese analise gebruik te maak, gevolg deur Tronto's (1993) se konseptualisasie van omgee, wat bestaan uit vier fases van praktyke en mede deugszaamheid. Deur gebruik te maak van Tronto's (1993) se raamwerk, lewer ek bevindinge oor deelnemers se ervarings. Deelnemers se stories wat verband hou met omgee en om bedag te wees, om te versorg en verantwoordelik te wees, versorging en om bevoeg te wees as ook die ontvang van omgee en om reageerend te wees met kinders met gestremdhede, word geillustreer. Deur 'n etiek van versorging teoretiese raamwerk te gebruik, beklemtoon ek die belangrikheid daarvan om te leer uit versorgers se ervaringe in orde om maniere te vind vir die skepping van 'n gemeenskap wat meer omgee – waar die behoeftes van beide die versorgers en die wie versorg word – die kinders met gestremdhede in die geval – omgesien en vervul word, en waar die rol van versorging meer regverdig versprei word. Na die beperkinge van die studie bepsreek is, vergelyk ek die bevindinge met reeds bestaande Suid- Afrikaanse literatuur en versorgings etieke, en stel ek implikasies voor vir navosing, diens en aktivisme.

*Sleutelwoorde:* Versorgers, Ouers, Moeders, Vaders, Familieledede, Gestremdhede, Kroniese siekte, Kinderversorging, Etiek van versorging, Suid- Afrika

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## Chapter 1: Introduction to Research Topic and Rationale for Project

Although estimates of the prevalence of children with disabilities in South Africa are poorly validated and inadequate (The African Child Policy Forum [ACPF], 2011), census-based estimates for the percentage of children aged 0 to 19 with disabilities range between 5% and 17.5% (Statistics South Africa, 2005, 2010, 2014b). What do I mean when I refer to children with a *disability*? The concept of disability is complex, multi-dimensional and hotly debated and has changed with time (World Health Organization [WHO], 2011). While a detailed discussion is not the focus of this thesis, I will provide a definition by the International Classification of Functioning, Disability and Health, which defines disability as difficulties in any area of an individual's functioning, such as impairments, activity limitations, and/or participation restriction in any area of life, which result from interactions between an individual with a health condition and contextual factors such as their environment or personal factors (WHO, 2001).

In South Africa, many children with disabilities experience exclusion from health and education services, amongst other support infrastructure, which are crucial for their development (Department of Social Development [DSD], 2009). Often families and others who care for these children also experience a lack of support, as they struggle to care for their children and themselves with limited resources (Geiger, 2012), and in the context of poverty, limited access to health care facilities, and repercussions of HIV and AIDS (ACPF, 2011). Despite the existence of government policies which outline services for people with disabilities, such services are seldom prioritized or sufficiently coordinated (Adnams, 2010; Geiger, 2012). Stemming from inadequate or inaccessible services, nongovernmental organisations sometimes step in to offer support and services to people with disabilities and those who care for them (Adnams, 2010; Geiger, 2012).

## Disabled Children's Action Group: DICAG

An example of such an organisation in South Africa is the Disabled Children's Action Group (DICAG), formed in 1993 by and for the parents of children with disabilities. DICAG is actively involved in advocacy and development of caregivers and their children with disabilities.<sup>1</sup> The organisation supports and runs programmes and initiatives involving prevention, rehabilitation, social integration, parent mobilisation, and empowerment of children with disabilities, their siblings and parents. In particular, DICAG aims to support children with disabilities and their caregivers who live in difficult circumstances due to poverty, environmental location, racial oppression, and/or severe disability (DICAG, n.d.).

As a part of an ongoing collaboration between my supervisor and DICAG, in December 2015 I met with Ms Ambrose, DICAG's national coordinator, to discuss the research priorities and needs of their organisation. Amongst a myriad of other challenges faced by DICAG and its members, Ms Ambrose described some of the difficulties experienced by caregivers of children with disabilities, including those who work in DICAG-affiliated day-care centres around South Africa. Reporting from her extensive involvement with caregivers of children with disabilities, Ms Ambrose talked about how many caregivers are overworked, and may experience trauma as they care for their own or others' children with disabilities who have been abused. Despite heavy workloads and stressful encounters involved in their care-work at home or day-care centres, caregivers tend to have few, if any, opportunities to process their experiences, to rest, or to heal. Ms Ambrose explained how such

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<sup>1</sup> There are debates about the best terminology to use. Depending on theoretical and political orientation, disability studies scholars may choose to use *people with disabilities* or *disabled people*. The terminology of disabled people links to the social model of disability, which says that people are *disabled* by society, and locates the barriers of functioning in an individual's environment, rather than focussing on a person's impairments (Goodley, 2011). The term *people with disabilities* is employed to emphasise people's humanity before their impairment. Goodley (2011, p.9) states that despite differences in preferences of terminology, disability studies scholars share the desire to use language which, "does not demean, is culturally sensitive and recognises the humanity of disabled people before disability or impairment labels." When I spoke with the coordinator of DICAG, she emphasised that as an organisation they prefer the terminology *people with disabilities*, because it moves away from identifying or labelling people as *disabled*. Because this project was in support of and collaboration with DICAG, I chose to use their preferred terminology. Therefore I refer to *children with disabilities* throughout this thesis.

experiences sometimes take tolls on caregivers' well-being, as well as that of their families, and the children for whom they care.

Ms Ambrose emphasised the need to listen to and investigate the experiences of these caregivers, in order to better understand their experiences, as well as to advocate for resources and policies to support caregivers and the important work which they do. Specifically, Ms Ambrose spoke about three DICAG-affiliated centres in semi-rural areas in the Western Cape, where caregivers of children with disabilities work or attend support meetings. These centres comprised an edu-care centre and an orphanage for children with disabilities, and a parent support centre where parents of children with disabilities attend support meetings once a month. These centres will be further described in Chapter 4. Ms Ambrose expressed that investigating the caregivers' experiences at these centres, and writing a report with the findings might help to support the individual caregivers, the centres, the children, and DICAG as a national organisation.

### **Research Questions, Aims and Objectives**

With this impetus, I opted to investigate the experiences of caregivers at the three semi-rural DICAG-affiliated centres in the Western Cape. The guiding research questions for this project were:

1. What are the experiences of caregivers who work at DICAG-affiliated care centres for children with disabilities in semi-rural Western Cape?
2. What are the experiences of caregivers who attend support meetings at a DICAG-affiliated parent-support centre for parents of children with disabilities in semi-rural Western Cape?

As a part of answering the above questions, I aimed to investigate various facets of caregivers' experiences, including but not limited to: challenging and rewarding aspects of caregiving; coping mechanisms; support received and support needs; skills and training for caring for children with disabilities; the ways caregivers think and feel about caregiving; and how caregiving impacts various domains of caregivers' functioning and daily lives.

The overall objectives of this project were to give these caregivers an opportunity to voice their needs and experiences; to increase researchers', health professionals', and other stakeholders' understandings of caregivers' experiences and support needs, by writing reports and publishing articles with the project's findings; to enable DICAG and its affiliated centres to access funding and support, by using reports from this project as motivation; and to support DICAG, its affiliated centres, caregivers, and the children in their care.

## **Overview of Chapters**

### **Chapter 1**

In this chapter I introduced the research topic by briefly describing the South African context for caregivers of children with disabilities, and briefly mentioning some of the challenges they face. After describing the impetus of the study which involved partnering with DICAG, I presented the research question: exploring the experiences of caregivers with disabilities at DICAG-affiliated centres near Cape Town, South Africa. Thereafter I described some of the associated aims and objectives of the project, and the rationale for the study, including supporting DICAG, its affiliated centres, and caregivers of children with disabilities.

### **Chapter 2**

In Chapter 2, I will report on some of the South African policies related to caregivers of children with disabilities, and provide a review of some of the recent local child-disability caregiving literature, in order to give context to this study, and provide points of reference for comparison in the discussion.

### **Chapter 3**

In Chapter 3 I present an overview of an ethics of care theoretical framework, by referring to some of the significant contributors to this theory, and expounding on the framework's relevance to experiences of caregivers of children with disabilities. I also suggest how this theoretical approach provides further rationale for investigating caregivers' experiences.

## **Chapter 4**

Chapter 4 comprises a detailed account of the methods which I followed in carrying out this research in attempt to answer the research question: What are the experiences of caregivers of children with disabilities at the DICAG-affiliated centres. In this chapter, I explain the research design, my approach to ethical engagement in the study, the participants and sampling, data collection, and data analysis methods.

## **Chapter 5**

In Chapter 5, I present the findings from the analysis of the data, which comprised transcriptions of interviews with caregivers of children with disabilities at the centres. I present the findings using Tronto's (1993) conceptualisation of care, which comprises four stages of care and their associated virtues: caring about and being attentive; taking care and being responsible; caregiving and being competent; and care receiving and responsiveness. I also illustrate how in participants' experiences these phases of care are intertwined.

## **Chapter 6**

In Chapter 6, I begin by discussing some of the limitations of this study. Thereafter I explore some of the links between the findings from this study, those in other South African publications, and an ethics of care framework. Finally, I present some tentative recommendations based on the findings, and reflect on the value of the research project, with reference to the original research question, aims and objectives of the study.

## Chapter 2: Literature Review

To give context to this research project and strengthen its rationale, in this chapter I describe some of the South African government's policies relating to caregivers of children with disabilities. I also present some of the local published research about caregivers of children with disabilities in South Africa, which emerged in part from a larger project comprising a systematic review on this topic.

### **Policies Linked to Caregivers of Children with Disabilities**

The South African government has signed or published a number of policy documents regarding the rights of children with disabilities and their caregivers. In 1996, South Africa signed the United Nations Convention on the Rights of the Child (UNCRC), and in 2007 the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Based in part on concepts in these documents and various Acts in the South African Constitution, the Department of Social Development (DSD; 2009) published the *Integrated National Strategy on Support Services to Children with Disabilities*. This document outlines government strategies for implementing the rights of children with disabilities, including strategies related to their caregivers. The report highlights the importance of listening to the views of children with disabilities, their parents, and other caregivers, concerning issues related to decision-making processes which affect these populations. In addition, the report states that psychosocial interventions, life skills training, parental programmes, respite care services, and other forms of community support should be accessible to families with children with disabilities, to help them cope with the challenges they face, and “enable them to function optimally in society” (DSD, 2009, p.31-32). In a joint paper comprising a situational analysis of children with disabilities in South Africa, the DSD, Department of Women, Children and People with Disabilities, and UNICEF (2012) emphasise the necessity of parent and caregiver support, including ensuring that caregivers of children with disabilities have access to information about training and resources, both for themselves and for their children.

One group of carers of children with disabilities who require training and support is teachers (DSD et al., 2012). In 2001, the Department of Education (DoE; 2001) published the white paper on inclusive education, which aims to address barriers to learning of students, both by strengthening the support offered by special schools, and by changing mainstream schools to be more accommodating and accessible to people with disabilities.

The Social Assistance Act (Republic of South Africa, 2004) includes the care dependency grant for parents, foster parents, and other primary carers of a children requiring permanent care or support services due to mental or physical disability. To qualify for this grant, a child must undergo medical assessments or proof of disability, and the caregiver must be within a certain income or means threshold (Republic of South Africa, 2004).

Despite policies advocating for the support of caregivers and children with disabilities, and progress in achieving associated goals to some extent, uncoordinated and inadequate government systems and programmes mean that many South African children and their caregivers do not receive the support they need (DSD, 2009).

### **Literature Search Strategy**

In attempt to explore the existing research concerning caregivers of children with disabilities, I conducted literature searches across several databases. While I was aware of an extensive international literature, I chose to investigate and focus on the South African literature in this thesis. I was interested in any research outputs which measured outcomes of caregivers of children with a disability, particularly in a South African context, and this informed the development of a search strategy. Accordingly, four key words formed the basis of a Boolean search query for publications related to caregivers of children with disabilities: *caregivers*, *children*, *disability*, and *South Africa*, from which I created lists of synonyms and related terms for each of the key words through brainstorming, consulting with my supervisor, and scouring various documents. Appendix A provides details of the

search terms and databases searched. The search strategy forms part of a larger systematic review on the topic, that I will report on in future but is not part of this thesis.

### **Overview of Scope of Literature**

In this section I describe the scope of the South African child-disability caregiving literature emergent from this review, to help provide context for this research project. While the publishing dates of the retrieved results span from 1995 until 2016, in this thesis I focus on the more recent articles. The overview presented here includes methods employed in the research, the types of caregivers and disabilities reported on in studies; and different places of care.

#### **Foci and methods of studies.**

The South African studies about caregivers of children with disabilities employed a variety of research methods to investigate caregivers' lives and experiences. For example, Topkin, Roman, and Mwaba (2015) used the Knowledge of Attention-Deficit Disorder Scale (KADDS), a quantitative measure, to examine South African primary school teachers' knowledge about general features, symptoms and diagnosis, and treatment of attention deficit disorder (ADHD). At special schools for learners with disabilities, a group of researchers used focus groups to explore teachers' knowledge, attitudes, challenges, and experiences of providing sexuality and HIV education to learners with disabilities (de Reus, Hanass-Hancock, Henken, & van Brakel, 2015). As a part of the development of a training and support package for home and community based care (HCBC) workers in paediatric palliative care, Naicker, Richter, Stein, Campbell and Marston (2016) used photo-elicitation. Also known as photo-voice, this participatory action research method involved the HCBC workers taking photographs which captured their feelings and experiences of caring for chronically ill children in South African homes, and discussing the photographs and photo-taking process thereafter (Naicker et al., 2016). Greeff and Nolting (2013) used qualitative and quantitative measures to examine resiliency amongst South African parents of children with developmental disabilities. With a sample of families raising children with autism spectrum disorders (ASD), Schlebusch, Samuels and Dada (2016) used a

quantitative survey to investigate links between family routines, cognitive appraisal of how ASD impact family life, and family quality of life (FQOL). While the methods and foci of these studies vary considerably, they each have the potential to provide valuable information about caregivers of children with disabilities, some of which will be described in subsequent sections. The next two sections address the types of caregivers and places of care for children with disabilities that were mentioned in South African studies.

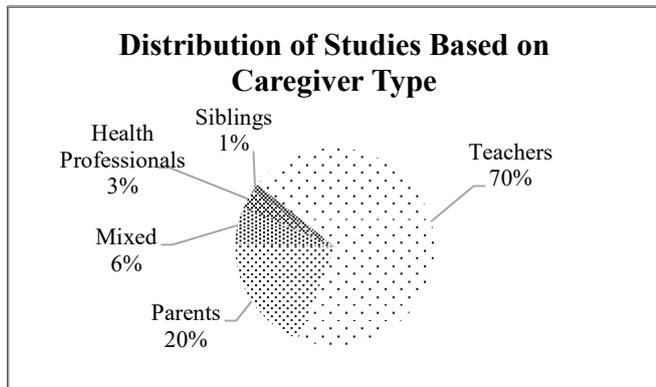
### **Types of caregivers.**

People with various occupations comprise caregivers of children with disabilities. Family members, health professionals and teachers might provide care to different extents and for different periods of time in children's lives. Caregivers of children with disabilities are by no means a homogenous population (Resch et al., 2010). Paid caregivers, such as teachers and nurses, may or may not have formal training in caregiving, and might work in a variety of locations such as hospitals, clinics, residential homes, community centres, schools, and private homes (Coetzee, 2016). Others who care for children with disabilities include more informal caregivers such as family members, comprising parents, grandparents, siblings or other relatives (Coetzee, 2016).

While the types of caregivers in the included study were limited by the search terms and inclusion criteria, I found it interesting to observe the representation of different types of caregivers in the studies, as well as which caregivers were not represented.

Figure 1

*Distribution of studies based on caregiver type, published between 1995 and 2016*



**Teachers.** As Figure 1 illustrates, about 70 percent of articles in this review published included teachers of children with disabilities as the participants. Perhaps because of the changes in educational policies in South Africa during this period, especially the movement towards inclusive education, there are a large number of studies investigating teachers' experiences of caring for children with disabilities; in fact, many of these studies use inclusive education as a focal point for the research (e.g., Nel, Engelbrecht, Nel, & Tlale, 2014; Ntombela, 2011; Savolainen, Engelbrecht, Nel, & Malinen, 2012).

**Parents.** Although parents are also influenced by policy changes such as inclusive education, and most parents have always had to—and continue to—care for their children with disabilities, there seems to be a much smaller body of research about these carers in South Africa (see Figure 1). The high ratio of parent caregivers to teacher caregivers also raises questions about why there is proportionally so few research outputs about parents' experiences than those of teachers caring of children with disabilities.

One of the other trends in the South African research publications was that there were many more studies specifically about mothers than there were about fathers of children with disabilities—more than 15 about mothers (e.g., Muthukrishna & Ebrahim, 2014; Negota & Mashegoane, 2012; Tancred & Greeff, 2015), and only one about fathers (Martins, Walker, & Fouché, 2013). Some studies

about parents included both mothers and fathers, but even in these cases, there were generally at least double the number of mother participants than father participants (e.g., Erasmus, Bornman, & Dada, 2016; Mall & Swartz, 2011; Popich, Louw, & Eloff, 2006). This trend is congruent with the findings of researchers who have written about the gendered burden of care, which refers to how women tend to carry the majority of caregiving responsibilities in society, including for children, and including children with disabilities (Coetzee, 2016; Kittay, Jennings, & Wasunna, 2005; Resch et al., 2010).

**Health professionals.** Health professionals in full time care of children with disabilities comprised another type of caregiver in these studies. Articles about these caregivers tended to report on multiple health professionals' experiences, including nurses, various therapists, and doctors who worked with children with disabilities. Two of the five studies in this category involved health professionals who worked in mental health care facilities with youth in South Africa (Newman, Maggott, & Alexander, 2015; Smith, Strümpher, & Morton, 2015).

**Siblings.** The final type of caregiver included in these studies was siblings of children with disabilities. While a few articles included siblings amongst other family caregivers, only two specifically focussed on the experiences of siblings (Hansen, Harty, & Bornman, 2016; Opperman & Alant, 2003). Hansen et al. (2016) reported that the children in their study had generally positive attitudes towards engaging with their younger siblings with severe language and speech disabilities. In a much earlier study with adolescents who had siblings with severe disabilities, Opperman and Alant (2003) concluded that adolescents reported receiving insufficient information and guidance about their sibling's disability. In addition, Opperman and Alant (2003) reported that adolescents in the study did not easily speak about their feelings about their sibling with a disability, and reported limited engagement with their family. In support of further sibling research, authors of a systematic review in the United States argued that as members of families with a child with a disability, siblings are often intimately involved in family caregiving dynamics, and investigating their experiences is an important and under-researched endeavour (Vanegas & Abdelrahim, 2016).

**Gaps in the literature.** Only one of the articles in this review mentioned paid helpers. In the study, a review of 180 South African families raising children with autism spectrum disorders, Schlebusch et al. (2016) mention that 23 families in the study had live-in paid helpers. However, they do not reflect on what the role of these helpers was—whether caregiver, cleaner, and/or gardener, nor do they mention anything else about the paid helpers in the review, as far as I could tell (Schlebusch et al., 2016). It is possible that in more affluent countries, such as the USA, employing paid caregivers for people with disabilities is more common and accessible, while in South Africa very few families have this opportunity.

### **Places of caring for children with disabilities.**

Caregivers care for children with disabilities in many of corners society, from more formal institutions such as hospitals, to informal care centres and private homes.

**Formal institutions of care.** Paid caregivers in formal institutions, such as psychiatric hospitals, include nurses who care for individuals with intellectual and psychiatric disabilities. In primary health care clinics, nurses are often the main providers of care and services for people with disabilities (Mavundla, Toth, & Mphelane, 2009). Caregivers who work in disability sectors at hospitals and clinics are often underpaid and overworked, due to staff shortages, a lack of resources, and insufficient focus on the voices and needs of those who care (Capri & Buckle, 2015). Schools and edu-care centres where teachers, therapists, and other professionals attend to the needs of children with disabilities may also be places of care (Coetzee & Johns, 2016).

**Home-based caring.** One of the challenges facing families of children with disabilities is the scarcity of schools and early childhood development centres which have the facilities and services to adequately support children with disabilities in South Africa, particularly in rural areas (Ben-David & Nel, 2013; Geiger, 2012; Kromberg et al., 1997; Mathye & Eksteen, 2015). An additional struggle is that few South African families have the financial resources to afford employing private caregivers to look after their offspring with disabilities (McKenzie, McConkey, & Adnams, 2013). As a result of the

dearth and cost of other care options, primary caregiving responsibilities for people with disabilities in South Africa often fall to family members, commonly mothers (McKenzie, 2016).

**Community-based centres.** Faced with obstacles trying to find day-care in poor or rural areas in the Western Cape, some mothers have taken initiative and started special care centres for their children with disabilities (Geiger, 2012). Some of these community-based centres have grown into larger, more formal care centres for children with disabilities, supported by other mothers with similar needs (Geiger, 2012). However, even after qualifying for government funding, these centres tend to have far too few staff for the number of children, very poor or no pay for the caregivers, few training opportunities for the caregivers, and far too few resources (Geiger, 2012). Consequently, the care that the staff can provide is often limited to basic essentials, such as medication, food, hygiene, and physical containment, and there is little time or means to stimulate or support the children in ways essential for their optimal development (Geiger, 2012). The DICAG-affiliated care centres in this project are examples of community-based centres.

### **Caregiver Experiences in South Africa**

Having reported on the places of care, types of caregivers, and some of the research methods employed, in this section I describe elements of these caregivers' experiences from the recent South African publications. I have organised findings about caregivers' experiences into ways which caregivers think about disabilities; emotional experiences; social dynamics of caregiving; accessing infrastructure for children with disabilities; information, skills, and training for caring; and resource drains on self and their families which caregivers experience.

#### **How do caregivers think about disability?**

**Biomedical explanations.** One of the many ways which caregivers may conceptualise disability is through biomedical explanations. For example, caregivers may view their child's condition as hereditary (Keikelame & Swartz, 2007; Martins et al., 2013). In a rural community in Limpopo Province, South Africa, Mathye and Eksteen (2016) explored mothers' and a grandmother's perceptions

of the causes of disabilities of the children in their care, most of whom had a diagnosis of cerebral palsy. Some caregivers mentioned biomedical factors, such as child head injuries, insufficient oxygen, and missed vaccinations, as well as maternal life-style factors such as stress, smoking and drinking during pregnancy as causes of children's disabilities (Mathye & Eksteen, 2016). In contrast to this, in a study about the experiences of mothers of children with schizophrenia which was also based in Limpopo Province, Negota and Mashegoane (2012) report that biomedical explanations of disability did not emerge in mothers' descriptions of causes of their children's disability, and the authors argue that in that rural African context, medical models of mental illness are not widely known (Negota & Mashegoane, 2012).

**Religious beliefs.** Alternatively, or in addition to understanding disability in terms of biomedicine, caregivers may make sense of their child's disability in terms of their religious beliefs. The capacity for caregivers to hold multiple explanatory models is illustrated in a study where caregivers of children with disabilities in the Western Cape felt that both doctors and traditional healers had their roles to perform in the rehabilitation process (Masasa, Irwin-Carruthers, & Faure, 2005).

In many of the studies, caregivers spoke about bewitchment and curses as reasons for their children's disabilities (e.g., Mathye & Eksteen, 2016; Mudhovozi, Maphula, & Mashamba, 2012; Negota & Mashegoane, 2012). Other explanations amongst caregivers related to their perceptions of God's role in their children's disabilities. Some caregivers view their children's disabilities as God's will (Mathye & Eksteen, 2016; Radzilani-Makatu, 2014). Linked to this notion, caregivers in a few recent South African studies conceptualised their children with disabilities as gifts from God (Mathye & Eksteen, 2016; McKenzie, 2013; Muthukrishna & Ebrahim, 2014). In an unusual study because of its focus on fathers' experiences, Martins et al. (2013) describe how one father used religious coping to deal with the stresses of raising a child with an ASD; the father spoke about praying, and emphasised his belief that God would cure his child of his condition. According to Mudhovozi et al. (2012), some caregivers believed that their child's disability was a punishment from God. In a study based in a large

informal settlement near Johannesburg, one caregiver expressed her concern about how people in her community judge her child, such as other mothers who say that her child's disability is a punishment from God (De Sas Kropiwnicki, Elphick, & Elphick, 2014).

***Human faults and personal responsibility.*** The belief that a child's disability is a punishment from God connects to the idea of disability being due to human fault. One mother expressed this idea as following, "With all that I did in the past, when I realised that my child was disabled, I knew that God was punishing me for all the wrong doing" (Mudhovozi et al., 2012, p.153). Similarly, attributing a child's disability to a mother's life-style habits such as smoking and drinking during pregnancy, as mentioned by participants in Mathye and Eksteen's study (2016) also locates the cause of the disability with the mother. Connected to this idea, some caregivers of children with disabilities may feel that their children's disabilities are due to some error of their own (Masasa et al., 2005).

***Asking questions.*** One of the pertinent trends in how caregivers of children with disabilities think about disability is the questioning they engage in. For example, in an interview excerpt presented by Saville Young and Berry (2016), a mother of a son with physical and developmental disabilities says she has asked many questions, some of which she's still waiting for answers, like why autism exists, and why so many people have autism. Another questioning process evident in this caregiving literature is caregivers wondering, "why me" with regards to their having a child with a disability (Mweshi & Mpofo, 2001; Saville Young & Berry, 2016)

### **How does it feel for caregivers to care?**

Alongside how caregivers think about disability, the emotions which caregivers feel are also important for understanding their experiences.

***Stressed and distressed.*** Reading stories about caregivers' experiences, it becomes clear that stress is a common part of many caregivers' daily lives (Coetzee, 2016; Sandy, Kgole, & Mavundla, 2013; Thsitake, Pengpid, & Peltzer, 2013). For example, more than 80% of the child-care workers in Thsitake et al.'s (2013) study reported feeling stressed due to caring for children with special needs.

Parents of children with learning disabilities in Sandy et al.'s (2013) study expressed that they experienced caregiving as stressful, particularly when they had to take care of other responsibilities, such as household chores.

Coetzee (2016) argues that many South African family caregivers are exposed to additional stressors which are not as common in better resourced countries, due in part to less structural support for caregivers and children with disabilities. Feeling overwhelmed, demotivated and unsatisfied with their work can contribute to feeling stressed for some caregivers of children with disabilities (Coetzee, 2016). When children have more severe physical disabilities, psychiatric diagnoses or behavioural difficulties, caregivers may also experience more stress (Coetzee, 2016).

***Exhausted and burnt out.*** Parent caregivers in Sandy et al.'s (2013) study felt that caring for children with learning disabilities, on top of other responsibilities, was not only stressful, but physically and emotionally exhausting too. Part of what exacerbated their stress and fatigue was the lack of respite from caring responsibilities (Sandy et al., 2013). Caregivers in other South African studies also reported feeling burnt out (Mathye & Eksteen, 2016; Naicker et al., 2016).

***Lonely, unappreciated and uncared for.*** Opperman and Alant (2003) suggest that adolescent siblings of children with disabilities might feel lonely due to other people's prejudices about their siblings with disabilities. Caregivers may feel lonely when they do not have support with their caring responsibilities (Mhaule & Ntswane-Lebang, 2009). In addition, some caregivers might feel that their caring role is not appreciated (Mhaule & Ntswane-Lebang, 2009). Geiger (2012) illuminates how sometimes caregivers needed to feel supported, nurtured and understood, in order to be able to provide warmth and care to the children with whom they work.

***Angry and frustrated.*** Anger and frustration also emerged as part of the emotional experiences of caregivers. Some caregivers felt frustrated and angry with the government for not providing sufficient support services to help them care for their family members with schizophrenia (Mhaule & Ntswane-Lebang, 2009). Family caregivers of children with learning disabilities also experienced anger

and frustration, both towards the recipients of their care, as well as towards health professionals (Sandy et al., 2013). These caregivers attributed their frustrated emotions to having to deal with challenging behaviours of their children with disabilities on a frequent basis (Sandy et al., 2013). In terms of their anger towards health professionals, caregivers felt they did not offer them adequate support, nor sufficiently involve them in care decision-making processes about their children (Sandy et al., 2013).

***Worried, anxious and fearful.*** Worry and anxiety also seem to be common experiences of many caregivers of children with disabilities in South Africa. Participants caring for relatives with schizophrenia expressed worries about their own and their relative with schizophrenia's futures (Mhaule & Ntswane-Lebang, 2009). Some caregivers felt afraid when their ill relative was violent or aggressive, and felt both personally upset, and worried about how they might cause trouble for other people (Mhaule & Ntswane-Lebang, 2009). In a study with parents of prelingually deaf children, a parent expressed feeling worried about her child's behaviour, his getting angry, and her not understanding why (Moroe & Kathrada, 2016). Caregivers of children with learning disabilities also conveyed that they felt anxious, mostly as a result of having insufficient information about learning disabilities (Sandy et al., 2013). Another situation in which caregivers might experience anxiety is when leaving their child with another caregiver, especially if they are worried about the quality of care their child will receive (Elphick, Elphick, & De Sas Kropiwnicki, 2014). De Reus et al. (2015) report that teachers of learners with disabilities felt worried that the learners did not have thorough understandings of sexuality or relationships, nor much awareness of the risks of sexual activities.

***Ashamed and embarrassed.*** Some caregivers may feel ashamed of the person for whom they care (Mhaule & Ntswane-Lebang, 2009). They expressed that feeling embarrassed or shameful meant that they did not talk to other people about their ill relative, and sometimes did not attend community gatherings due to fearing having to talk about their ill relative (Mhaule & Ntswane-Lebang, 2009).

***Loving, compassionate and connected.*** Amongst many negative emotional experiences, some caregivers reflect on more positive emotional aspects of caregiving. Coetzee (2016) mentions how

caregivers may feel a sense of companionship with their children, which adds meaning to their lives. Educators in an inclusive learning context expressed love and acceptance towards the learners experiencing barriers to learning (Magare, Kitching, & Roos, 2010).

***Empowered.*** Caregivers in Sandy et al.'s (2013) study articulated that having information about how to care for their children made them feel empowered, and able to advocate on behalf of their children. The discoveries from Geiger's (2012) study illustrate how engaging with practical and context-relevant training can empower caregivers to provide better support and skill development to children with disabilities, as well as gain more personal enjoyment from the process.

### **What social dynamics form a part of caregivers' experiences?**

The social support and dynamics which caregivers experience as they care for children with disabilities may vary, depending on the context.

***Social support for caregivers.*** Some caregivers experience a lack of family support (Mathye & Eksteen, 2015; Mhaule & Ntswane-Lebang, 2009). Participants had to take care of their entire households, including but not limited to the relative with a disability, and therefore were forced to stay at home all the time (Mhaule & Ntswane-Lebang, 2009). This made them feel isolated from their communities (Mhaule & Ntswane-Lebang, 2009). Caregivers in Sandy et al.'s (2013) expressed their desire for more social support, by proposing that caregivers have a mentor or buddy to talk to on a monthly basis to help them process the stresses of caregiving, and learn from a more experienced caregivers.

***Social dynamics with recipients of care.*** Some caregivers spoke about how their relative with schizophrenia could be demanding or manipulative, resulting in conflict in the family households (Mhaule & Ntswane-Lebang, 2009). Participants also reflected on some of the loving dynamics of their relationships with the children in their care (Mhaule & Ntswane-Lebang, 2009).

***Social dynamics with other caregivers at caring facilities.*** Another part of caregiver social dynamics includes the attitudes, communication, and collaboration of caregivers with each other.

Caregivers in Mathye and Eksteen's (2015) investigation said that their interactions with other caregivers were sometimes difficult and made the caregiving process more demanding. To add to this, a lack of continuity of caregiving staff at care facilities made caregiving more challenging (Mathye & Eksteen, 2015).

***Stigma and marginalisation in community.*** Mathye and Eksteen (2015) report that caregivers felt that negative perceptions of children with disabilities in the community were sometimes difficult to deal with. When they choose to care for a relative with a disability, some caregivers experienced rejection from their partners or other family members (Mhaule & Ntswane-Lebang, 2009). Caregivers recounted experiences of discrimination in their communities, due to negative attitudes and prejudices, held by family and other community members, about children with learning disabilities and their caregivers (Sandy et al., 2013).

#### **What is it like for caregivers to access necessary infrastructure?**

***Access to transport and caring facilities.*** Caregivers reported challenges with accessing social assistance grants, health-care services, educational and recreational facilities, and other public infrastructure (Mathye & Eksteen, 2015). To add to this, insufficient transportation and affordable housing, alongside poverty in a rural, made caregiving more difficult (Mathye & Eksteen, 2015).

***Access to professional support, medication, equipment and assistive devices.*** Some caregivers felt they lacked sufficient professional support in looking after their children (Mathye & Eksteen, 2015; Sandy et al., 2013). They also spoke about how sometimes the clinic did not have stock of the drugs prescribed for their ill relative (Mhaule & Ntswane-Lebang, 2009). Mathye and Eksteen (2015) reported that a lack of equipment and materials for proper care of children with disabilities was one of the challenges experiences by caregivers.

#### **What information, skills and training do caregivers receive and need?**

***Importance of context relevant training.*** Based on their study, Sandy et al. (2013) advocate for context relevant caregiver training and education which is informed by the needs and styles of the

caregivers. Geiger (2012) reports that complex individualised interventions, advocated for in more well-resourced centres, were near impossible for caregivers in the under-resourced care centres to implement, and that more context-appropriate approaches were much more helpful.

***Scarcity of skills and information.*** Many caregivers in South African studies felt they lacked sufficient skills for caring for their child with a disability (Mathye & Eksteen, 2015; Mhaule & Ntswane-Lebang, 2009; Sandy et al., 2013) Caregivers of children with disabilities in a number of South African studies felt that they did not have enough information about their care recipients' disabilities, rehabilitation, and care needs (Mathye & Eksteen, 2015; Sandy et al., 2013).

### **What resource drains do caregivers experience?**

Most caregivers in South African studies expressed concerns about limited finances and the implications thereof. Having to provide care for a child with disabilities seven days a week often puts considerable strain on family finances, as caregivers are unlikely to have time to earn an income due to caregiving responsibilities (Geiger, 2012; Mhaule & Ntswane-Lebang, 2009; Sandy et al., 2013). Some caregivers in South Africa struggle to provide clothing and food for their children with disabilities (Mathye & Eksteen, 2015; Sandy et al., 2013). Some caregivers claimed that the grant they received from the government for their children with disabilities was inadequate for meeting their children's needs (Sandy et al., 2013).

### **Intersection of poverty and rurality in caregivers' lives.**

The location of caring, including environmental factors such as how rural or urban the setting is, and what the community context around the caregivers is, can influence caregiving experiences (Darling & Gallagher, 2004). Some of the examples mentioned in the literature review showcase the scarcity of resources for caregivers and their children in rural and poor areas. The findings also reveal how many aspects of caregivers' personal and environmental contexts interact to inform the ways they experience caregiving, from access to resources and infrastructure, to skills and training, social interactions, emotional experiences, and cognitive understandings of disability.

## **Linking South African literature to rationale and research questions**

Exploring the recent South African literature about caregivers of children with disabilities informed this research project in important ways. Firstly, the varied nature of caregivers' experiences illuminated in the South African literature provided further rationale for exploring the particular experiences of this group of caregivers. Secondly, the complex interplay of factors involved in caregivers' thoughts and feelings, their relationships with children with disabilities and others in their environments, and their access and use of resources as they care for children with disabilities, provide motivation for exploring these dynamics of experience in this particular group of caregivers, in order to potentially inform interventions to enhance caregivers' well-being, quality of care, and other aspects of their lives. In these ways, the literature review informed the aims and strengthened the rationale for addressing the following research questions, presented in Chapter 1, and restated here as a reminder for the reader.

### **Aims and research questions restated.**

Having reviewed the relevant literature, I aimed to investigate various facets of caregivers' experiences, including but not limited to: challenging and rewarding aspects of caregiving; coping mechanisms; support received and support needs; skills and training for caring for children with disabilities; the ways caregivers think and feel about caregiving; and how caregiving impacts various domains of caregivers' functioning and daily lives.

Because I was interested in the experiences of caregivers of children with disabilities, in the particular context of DICAG-affiliated centres in the Western Cape, South Africa, the research questions of this project were:

1. What are the experiences of caregivers who work at DICAG-affiliated care centres for children with disabilities in semi-rural Western Cape?
2. What are the experiences of caregivers who attend support meetings at a DICAG-affiliated parent-support centre for parents of children with disabilities in semi-rural Western Cape?

The research questions were linked to the aims and the literature, and to the organisational rationale described in Chapter 1, which included objectives of supporting DICAG, the care centres, caregivers, and the children with disabilities in their care.

### **Linking South African literature to an Ethics of Care**

As well as informing the rationale and aims of the study, conducting the literature review alerted me to some of the different theoretical approaches to the topic of caregiving for children with disabilities. One of the frameworks, called an ethics of care, seemed particularly relevant for this project. The following chapter will describe ethics of care as the theoretical framework which underpins the study both by supporting its rationale and informing its methodology, including data analysis and the presentation of the findings and implications of the study.

### Chapter 3: Theoretical Framework

As mentioned at the end of the previous chapter, the conceptual framework which I chose to undergird this study is that of an ethics of care. Some early seminal authors and works on this topic include Carol Gilligan's (1982) *In a Different Voice*, Nel Noddings's (1984) *Caring*, Joan Tronto's (1993) *Moral Boundaries*, Virginia Held's (1993) *Feminist Morality*, and Eva Feder Kittay's (1999) *Love's Labor*. All of these authors have reworked, updated and/or developed their theories about care ethics since. While some differences between these theorists' approaches to care ethics exist, I do not focus on these here. Rather, I present my interpretation and understanding of an ethics of care, and describe why an ethics of care is a relevant framework for this study.

#### What is an Ethics of Care?

An ethics of care is a set of moral principles which put caring relationships and connection to others at the centre of morality (Kittay, 2013).

**What is ethics?** Ethics can be defined as the philosophical study of morality (Noddings, 2013). Ethical theory, also called moral philosophy,

Refers to the systematic effort to understand moral concepts and justify moral principles and theories. It analyses key ethical concepts such as "right," "wrong," and "permissible." It explores possible sources of moral obligation ... [and] seeks to establish principles of right behaviour that may serve as action guides for individuals and groups. ... Moral principles concern standards of behaviour; roughly speaking, they involve not what is but what ought to be. How should I live my life? What is the right thing to do in this situation? (Pojman & Fieser, 2012, p.3)

**What is care?** Tronto (1993) conceptualises care as being both *practice* and *virtue*, which are intertwined. Care involves the virtue of being *attentive* in order to practice *noticing* the need to care; the virtue of *taking responsibility* is required for *responding* to a need for care; the virtue of *competence* is necessary in order to *do the work* of caring successfully; and the virtue of *responsiveness* is important

for the practice of engaging with and considering the experiences of the *receivers of care* (Tronto, 1993). Tronto (2010) emphasises care as an inherently relational practice.

In a related conceptualisation, Kittay (2002), describes care as comprising three facets: *labour*, *attitude* and *virtue*. Care as a labour involves the work of attending to the needs of ourselves and others. The attitude of being caring refers to being invested in the one in need's wellbeing, including having a positive emotional bond with the person. Kittay argues that having a caring attitude enables the person caring to be open to understanding and responding the needs of another person. Therefore, although the labour of care can be done without the accompanying attitude, it will not be good care unless the attitude accompanies the labour. When one caringly and consistently attends to another's needs, "even when it is difficult and disadvantageous to us", this cultivates the virtue of care (Kittay, 2002, p.260).

### **What are the fundamental concepts of an ethics of care?**

In *The Ethics of Care: Personal, Political, and Global*, Virginia Held (2006) proposes what she posits to be the common features of the varying versions of ethics of care. I found her presentation very helpful, and have drawn quite extensively from her writing in the descriptions below, while also adding from other theorists.

#### **Moral salience of caring.**

Primarily, an ethics of care emphasises the moral salience of our responsibility to respond to and meet the needs of people in our lives (Held, 2006).

#### **Moral agents: Relational and dependent.**

In contrast to traditional moral theories which focus on humans' independence and autonomy as the bases for morality, care ethicists bring attention to the dependency and relational nature of humans (Held, 2006; Kittay et al., 2005). Everyone experiences varying degrees of dependency throughout their lives, and moral theories which ignore this ignore a significant aspect of human experience (Held, 2006; Tronto, 1993).

Kittay et al. (2005) argue that when we change our focus from independence as our goal, to human relationships and dependency as our primary moral concerns, the emphasis of the moral discussion shifts to “fashioning a society in which the longterm demands of care are equitably distributed and organized with attention to the relationships that give our lives meaning” (p.454).

### **Moral relations.**

Dominant moral theories tend to assume moral agents who are independent, unrelated, indifferent to one another, and equal (Held, 2006). An ethics of care posits that this view does not reflect the reality of human relations, in which there are often significant power differentials between people, who are interconnected in various contexts, and may or may not have chosen their ties with those with whom they are in relationship. For example, in a family, there are power differentials between a child and her parents. When the child grows up, although she did not choose her parents, she may have obligations to care for her parents because of her relation to them. In this situation, the grown child is not a completely unconnected, autonomous being starting from scratch with abstract moral principles about whether or not, or how to care for her parents. The unchosen relation she has with her parents, her connection with them, plays a role in her moral deliberation about care. From an ethics of care perspective, all relations are not contractual. We do not choose all relationships from a blank, indifferent slate and then engage accordingly. Our positions in, for example, a family, play a role in our obligations, our choices, the consequences of these choices, and our feelings about these choices, as might be imagined in the example of the grown child caring for her elderly parents (Held, 2006).

An ethics of care not only brings attention to issues of position and power in familial relationships, but also in broader society. For example, people do not generally have a choice about the gender, racial, class, or cultural groups in which they are brought up, yet their connections with these groups are likely to nonetheless impact their sense of self, their experiences in the world, and their approaches to morality.

**Moral deliberating.*****Value of Particularity.****Particular contexts.*

“Moral decisions are, after all, made in real situations” (Noddings, 2013, p.3) Dominant moral theories tend to glorify universal moral rules- moral rules should be applicable to everyone, everywhere, at any time to be a good moral rule, and to this end they should be based on abstract rational reason in order to be void of bias, impartial to particular contexts. An ethics of care rejects the view that the more abstract the reasoning and universal the moral rule, the better (Held, 2006). It is important to note that an ethics of care does not reject universal rules for justice. Rather, as Kittay (2011) argues, an ethics of care can complement practices of justice by bringing contextual complexities of situations to light.

*Particular others.*

Dominant moral theories tend to view attachments to particular people, such as friends or family, as nonmoral, private preferences which are permissible only if confined by impartial moral norms. From an ethics of care perspective, the actual relationships we have with particular others are fully relevant to moral decision making (Held, 2006). Kittay et al. (2005) express how within an ethics of care framework, values such as attentiveness, responsiveness, and a sense of responsibility towards the well-being of *particular others* are at least as important as ideals such as rationality, impartiality and autonomy. In this context, an ethics of care advocates not only for the moral value of relations, but also for moral guidance to better relations (Held, 2006).

***Value of emotions.***

Dominant moral theories tend to emphasise reason and rationality, and reject emotions, as guides for determining what is morally right (Held, 2006). Such theories might argue that emotions can impede on universal moral norms; for example, emotions leading to loyalty or favouritism might interfere with the universal moral norm of impartiality (Held, 2006). In contrast to this, an ethics of

care, “typically appreciates the emotions and relational capabilities that enable morally concerned persons in actual interpersonal contexts to understand what would be best” (Held, 2006, p.10-11). In other words, care ethicists do not view emotions as necessarily impeding moral action, but rather potentially enabling moral action. For example, from an ethics of care perspective, we should cultivate emotions such as sensitivity, sympathy and empathy to aid us in caring, and to aid our ascertaining what is moral in certain situations (Held, 2006). Kittay (2011) writes that moral deliberation requires empathy, perceptual attentiveness, and emotional responsiveness, and not only reason. At the same time, other emotions such as anger can also be helpful towards the moral mandate of caring: For example, feeling angry because of somebody’s maltreatment might help, rather than interfere with, deciphering what is right and wrong in a situation. At the same time, an ethics of care does not dictate raw emotion as the ultimate guide to morality, but rather acknowledges the potential value of feelings when we reflect on and are educated about them (Held, 2006).

***Value of interdependent interests: Self-and-other together entwined (between egoist and altruistic)***

According to Held (2006), dominant moral theories tend to frame moral dilemmas as conflicts between universal moral principles and the selfish interests of individuals; this sets up a dichotomy of human character as either egoist or altruistic during moral conflicts. An ethics of care focuses on a space between these extremes: people in caring relationships are not acting primarily for their own interests, nor for those of humanity in general. Rather, they are seeking to promote their actual relationship with another particular person, so they are acting in the interests of self-and-other, together. The focus in moral dilemmas in relationships shifts away from conflict between an abstract self and the rest of humanity, and shifts towards enhancing cooperation between particular people for both of their well-being and that of their relationship (Held, 2006)

**Moral scope: Public and private life.**

Traditionally in moral theories, households are conceptualised as being in the private sphere of life, into which politics and government should not intrude (Held, 2006). Feminists argue that in the context of patriarchy, this division of public and private has disadvantaged women and children, by leaving them vulnerable to domestic abuse without outside interference, carrying a disproportionate weight of family labour, and often economically dependent on men. At the same time, this private life has been mostly left out of moral theory, which has given little concern to moral issues in the private realms of family and other relationships (Held, 2006).

A care ethics seeks to bring attention to the moral issues arising in contexts conceptualised as private (Held, 2006). A care ethic goes further than this, however, and advocates for public policies which focus more on care (Kittay, 2011). Kittay (2011) argues that larger society has the responsibility and obligation to support the care work that happens privately.

**Care for the caregivers.**

From an ethics of care perspective, from which care is the basis of morality and relationships, attending to the needs of caregivers is of utmost importance (Kittay et al., 2005). Caregivers often forsake their own needs to attend to the needs of others, and in contexts are overworked and unappreciated. Since care is the basis for a healthily functioning society, and because of the importance of valuing caregivers in the important work that they do, care ethicists emphasise the importance of caring for caregivers (Kittay et al., 2005).

**Note on disability rights critique of care and dependence.**

In this discussion about care and people with disabilities, it is important to mention how disability rights activists have brought attention to how persons with disabilities can experience care as oppressive (Kröger, 2009). From a disability rights perspective, individuals with disabilities need control over their lives, and neither this control nor their human rights should be compromised due to efforts of others to care (Kröger, 2009). While there may seem to be a conflict between the value of

independence of persons with disabilities from a disability rights perspective, and the value of interdependence from an ethics of care approach, Kröger (2009) argues that the gap between these approaches is becoming narrower, as the parties begin to recognise ways of learning from each other, and promoting the emancipation of people with disabilities as well as caregivers, both of whom may experience oppression as they navigate their engagement in the world. While I have taken an ethics of care approach in this project, and feel it is a helpful framework for the aims of this research, the emphasis on care and caregivers should not be in a way that diminishes the rights of children with disabilities.

### **How is an ethics of care relevant to a study about caregivers of children with disabilities?**

From an ethics of care approach, both the rights and care of children with disabilities, as well as the rights and care of their caregivers, are of utmost importance, and neither should be neglected (McKenzie, 2016). In addition, from this perspective, listening to caregivers' experiences is important from a moral point of view (Gilligan, 2011). Therefore, an ethics of care provides further rationale for investigating the experiences of caregivers, whose voices are often not acknowledged, to bring their important work into public light, and to find ways of supporting them.

The ethics of care theoretical framework not only contributed to the rationale for this study, but also informed aspects of the methodology, which I will describe in the following chapter.

## Chapter 4: Methodology

### Research Design

With the motivation of supporting DICAG as an organisation involved in disability care work, the impetus from my initial meeting with DICAG's national coordinator, Ms Ambrose (described in Chapter 1), the rationale supporting investigating the experiences of caregivers, and an ethics of care grounding the study, I decided to investigate the experiences of caregivers of children with disabilities at DICAG affiliated centres in semi-rural areas in the Western Cape, South Africa. I chose to use a qualitative approach, in order to explore and gain richer understandings of the lived experiences of these caregivers (Silverman, 2013; Spencer, Ritchie, Lewis, & Dillon, 2003). Because I wanted to understand the *particular* experiences, support needs and perspectives of these *particular* participants, I felt that a qualitative approach would be most appropriate. and least likely to limit the participants' responses. In collaboration with DICAG, I collected data from 23 caregivers of children with disabilities, using in-depth, semi-structured individual interviews to explore participants' caregiving experiences. I employed thematic analysis as a first layer, and Tronto's (1993) conceptualisation of care as a second layer of analysis of the data. In this chapter I describe the process of data collection and analysis, beginning with liaising with DICAG as an organisation, and ending with how I analysed the data.

### Considering Ethics

#### Procedural ethics.

Before commencing any collection of data, I applied for ethics approval from the Psychology Departmental Ethics Screening Committee (DESC) of Stellenbosch University (SU), and then from the SU Research Ethics Committee (REC). I received feedback from the REC, stating that my proposal was approved with stipulations. The REC provided detailed feedback, including constructive criticism which required my response, thoughts for my consideration, and positive feedback. The REC approval with stipulations, as well as my letter of response are provided in Appendices B and C respectively.

Appendix D contains the final notice of approval from the REC. Ms Ambrose, DICAG's national coordinator, provided organisational permission for the project (see Appendix E).

### **Informed consent.**

Part of the ethics approval application process involved thinking through the various stages of the project, and attempting to anticipate potential ethical issues, think how best to deal with them. Developing a clearly worded and thorough informed consent document for participants was an important part of this process. Reading the informed consent documents of other researchers, in particular one by Capri (2016) helped me to think about how to present important concepts in the informed consent document in a way that would be easy for participants to understand. Even as a postgraduate student, I sometimes read informed consent documents and struggle to understand what the researchers are trying to communicate. Because I did not know the extent of the education of participants and I wanted to make the informed consent accessible, it was important for me to write it in a way that was easy to understand, even for people who did not have a background or exposure to academia or research.

The informed consent document (see appendices F, G, and H for English, Afrikaans, and isiXhosa versions of the document) incorporated information about the purpose, method, and expected outcomes of the study, possible risks and benefits of participation, payment for participation, procedures for ensuring confidentiality, the rights of the participants, contact details of myself, my supervisor, and the Division for Research Development at SU, and a section where participants may sign to consent to participate if they choose. I informed the participants about my collaboration with DICAG in the project, and that the purpose of the interviews was for me to listen to their stories about their experiences of caregiving for children with disabilities. I told them that I would use a pseudonym for them when writing about them, and informed them about the recording, transcribing, and translating of the interviews, who might read and/or listen to the interview data, and the risks of being identified despite use of pseudonyms. I told participants that they would not receive payment for participating,

but that I would give them a blanket to say thank you, and travel money if they had to travel specially to come to the interview. I also informed the participants about where and how I would report on the data collected, which was in my thesis, and in a report for DICAG and the associated centres, to use as support for funding applications.

Because the interviews covered potentially sensitive topics, I encouraged participants to talk to a psychologist or counsellor if anything in the interviews unsettled or upset them. Accordingly, on the informed consent document, I provided the contact details of the Welgevallen Community Psychology Clinic in Stellenbosch where participants could consult a psychologist free of charge. I also told participants that if Stellenbosch was too far for participants to travel, I would find a psychologist or counsellor who practises closer to them, and would cover the cost of up to ten sessions. I told participants that I would be happy to assist them in accessing a psychologist or counsellor to process with, and asked contact me with my contact details, provided in the informed consent document, should they desire my assistance. Importantly, I emphasised that I wanted to respect the participants as far as possible, and asked them to tell me when my words or actions made them upset, uncomfortable, or confused. In addition, I asked participant if they had any questions after listening to or reading the informed consent, and requested that they please ask me these at any point. Lastly, I informed participants that they were free to choose not to participate, to stop participating, and to withdraw their participation at any time, without any consequences.

I asked Ms Ambrose for feedback about the informed consent document, as she was familiar with the participant population. Ms Ambrose said that the informed consent document was thorough and written in easy-to-understand language, but was quite long. She thought that this might deter some participants from reading the whole thing. Therefore, I decided that I would always verbally go through the informed consent in detail with participants, with an interpreter when necessary, and would then give them a copy to keep for future reference. Ms Ambrose also asked which languages the document would be in, due to some participants not being able to converse in English. I explained that

participants would be able to choose whether to have English, Afrikaans, and/or isiXhosa versions of the informed consent document, and that I would verbally outline the informed consent with participants in English or Afrikaans, or isiXhosa with the help of an interpreter, depending on participants' preferences. I encouraged participants to ask questions about the process, and did my best to answer any questions to their satisfaction.

### **Situational and relational ethics.**

Preparing my proposal for the ethics committees, reading and responding to the feedback from the committees, stimulated my thinking about potential ethical issues in the project, and prompted me to develop my method and principles of engagement with participants in such a way so as to- as far as possible- respect and do no harm to those I interacted with. For example, thinking about issues such as power dynamics between different parties involved in the research project, and language issues in collecting and analysing data helped to inform choices about sampling methods, interpreting during data collection, and translation of interview transcripts.

At many stages of the project, in meetings and emails with my supervisor, I found myself asking: But would it be ethical to...? And sometimes thinking: But I don't think I can ignore/do that- it wouldn't be ethical! Or: I don't feel that would be respectful of the participant/interpreter/organisation. Discussing and making choices about ethical conundrums which emerged at all stages of the project shaped how I conducted this research, which is why I am placing the *Ethical Considerations* section here, rather than at the end of the method, which is its usual place research reports. I hope it will give context to descriptions of engaging with DICAG as an organisation, sampling, data collection, and analysis that follow. As I describe different stages of the method, I include reflections about decision I made, many of which link to ethical issues. I address the informed consent form under *Data Collection*, as I feel it fits best as an introduction to how I collected data, as this always preceded the interviews when we visited the centres.

## **Setting the Scene**

### **Planning, preparation, and collaboration with DICAG.**

In December 2015 and March 2016, Ms Ambrose, the national coordinator of DICAG, and I met to discuss the research question, participant population, and DICAG-affiliated centres where I would collect data. We also discussed DICAG's involvement in the data collection process, and their organisational requirements for the project. To ensure that a DICAG representative was present during visits to the centres, to ensure that my research team treated the DICAG-affiliated centre participants respectfully, as well as to assist me with negotiating entry to the centres and meeting the coordinators, we decided that Ms Vuka, the Western Cape chairperson of DICAG would accompany me to each centre for data collection visits, and that I would pay her for her time. Because, as Western Cape chairperson, Ms Vuka had a position of power in the organisation with which the centres are affiliated, we decided that she would not sit in during interviews, but just accompany us to the centres. We also decided that an isiXhosa and English speaking interpreter would come with us on each centre visit, to assist with interpreting. In addition, we agreed that I would periodically email Ms Ambrose to update her about the progress of the project, and that Ms Vuka would also keep in touch with Ms Ambrose to inform her about her perspective of the project's progress. Ms Vuka and I followed through with these agreements, and kept in touch with Ms Ambrose throughout the project. In keeping with the collaborative nature of the project, I sent Ms Ambrose the informed consent documents and interview schedules for her perusal and approval before data collection ensued.

### **DICAG centres for participant recruitment and data collection.**

The centres where I chose to collect data were three DICAG-affiliated centres in semi-rural areas, within about a 60km radius of Cape Town, South Africa. The centres consisted of one edu-care centre for children with disabilities as well as able-bodied children, orphanage for children with disabilities, and one support centre for parents of children with disabilities. The edu-care centre provided education, early childhood development (ECD), play opportunities, and meals every weekday

to pre-school aged children from the area. The orphanage provided full-time accommodation to some children, while other children only attended the orphanage during the day. At the orphanage, the caregivers provided all meals for the children, and took care of children's other physical needs, such as attending to hygiene and warmth. The orphanage also had an edu-care component where children living in and out of the orphanage were provided with education, ECD, and play opportunities. The parent support centre, newly developed in the months before this project began, ran from the coordinator's house. The coordinator organised monthly meetings where parents and their children with disabilities could come together, eat food, connect with each other, and receive training or other input about caring for children with disabilities.

All the centres were located in poor areas. The edu-care and parent support centres were run from permanent concrete or brick dwellings which doubled as the coordinators' homes, in poor areas that consisted of mostly permanent concrete or brick dwellings. The orphanage was run from a set of containers on a plot of land surrounded by a fence, in the middle of a township.

## **Participants and Sampling**

### **Approaching the centre coordinators.**

After the initial planning and decision-making, Ms Ambrose phoned and spoke to the coordinators of the centres to introduce them to the research project.

After receiving ethics approval for the study in June 2016, I emailed Ms Ambrose a briefing document about the purpose of the research project—an abbreviated version of the information in the informed consent documents (see Appendices F, G, and H)—for Ms Ambrose to send to the coordinators of the centres. The purpose of the briefing document was to introduce the coordinators to the project, ask them to tell the caregivers at their centres about the project, and invite the coordinators and other caregivers at the centres to participate in our study. I included my and my supervisor's contact details in the briefing document, so that the coordinators could contact us if they had any questions about the upcoming project. I sent English, Afrikaans, and isiXhosa versions of the

document, so that all the coordinators and caregivers at the centres could access the document in their first language. Ms Ambrose then phoned the centre coordinators and arranged dates and times for our first visits to each of the centres. After doing so, Ms Ambrose emailed me these arrangements, and provided me with the contact details of the centre coordinators. Ms Vuka also assisted with arranging logistics, particularly for follow up visits to the centres.

### **Care centre participants.**

Having introduced the centre coordinators to the project via email and telephonically via Ms Ambrose, and having asked the coordinators to inform the caregivers about our project, I formally invited caregivers to participate when I arrived at the centres. I used purposive sampling at the edu-care centre and orphanage, and invited all the caregivers working there to participate in the study, which was appropriate as I was interested in all of their experiences, and the number of caregivers was small enough that interviewing all of them was feasible for this project (Silverman, 2013). The inclusion criteria for participants at these centres were that the individual be currently involved in care work with children with disabilities at one of the centres, and be available for interviews at the centre on the day arranged.

Unbeknownst to me, the edu-care coordinator not only invited caregivers who work there to be interviewed as was planned, but also invited parents of children with disabilities from that neighbourhood. As parents of children with disabilities living in that area and somehow associated with the centre, I chose to interview them as well, and felt that their participation would aid in answering the research question, although it was not initially the plan to include them. In addition, these parents arrived at the centre expecting to be interviewed, and expecting to receive a thank-you blanket about which they had been informed, and I felt it would be unethical to refuse to interview them. Altogether, there was a total of 20 participants at the care centres who agreed to be interviewed when we visited, including the surprise parent participants, the caregivers at the centres, and the coordinators at the edu-care centre and orphanage.

**Support centre participants.**

For the parent support centre, I used purposive convenience sampling, because it was not feasible for me to interview all 30 or more caregivers who attended meetings there. Ms Ambrose therefore asked this centre's coordinator to invite parents to participate in the study, and requested that she try to find about ten parents who would be potentially willing to participate. The inclusion criteria were that participants must care for at least one child with a disability, have attended at least one support meeting at the centre, and be available for interviews at the support centre on the day arranged. When we arrived to conduct interviews at this centre, there were only four participants, including the coordinator who is also a parent of a child with a disability. The coordinator explained that because it was the school holidays during that time, many parents had to stay at home with their children, and were therefore unable to participate in the project. I might have been able to interview more parents at this centre if I had chosen days during term-time to conduct interviews. Unfortunately, because I did not anticipate this, because of time-constraints with completing data collection, and because of trying to find times which would be suitable for myself, the interpreter, the centre coordinators, and Ms Vuka, it was not possible to visit the centre at other times to gather more data there. All the caregivers at the centres whom we invited to participate agreed to take part and were interviewed.

Table 1 presents the participants' pseudonyms, caregiving roles, associated centres, first languages, languages choice during interviews, race, and approximate age. Table 2 presents participants' pseudonyms, and some information about their child or sibling with a disability, including their role in participants' lives (e.g. daughter, son, or brother), the age and disability of participants' child. As Table 2 indicates, the disabilities of the children and siblings of participants varied.

Table 1

*Participant Caregiving Roles, Associated Centres, Languages and Demographics*

Pseudonym	Caregiving Role <sup>a</sup>	Associated Centre <sup>b</sup>	First Language	Language Choice <sup>d</sup>	Race	Approx Age
Rachel	Mother, Coordinator	Other (Pilot)	Afrikaans	English	Coloured	50+
Giselle	Mother	Parent Support	Afrikaans	Afrikaans	Coloured	40+
Robyn	Mother	Parent Support	Afrikaans	Afrikaans	Coloured	20+
Jacqui	Mother, Coordinator	Parent Support	Afrikaans	Afrikaans	Coloured	50+
Mandisa	Mother	Parent Support, Pre-school	isiXhosa	isiXhosa	Black	60+
Nozuko	Mother	Edu-care	isiXhosa	English	Black	20+
Thembi	Sibling, Care worker	Edu-care	isiXhosa	English	Black	20+
Pamela	Mother, Coordinator	Edu-care	isiXhosa	English	Black	50+
Nandipha	Mother	Edu-care	isiXhosa	isiXhosa	Black	40+
Nozibele	Care worker	Edu-care	isiXhosa	isiXhosa	Black	40+
Ndiliswa	Care worker	Edu-care	isiXhosa	isiXhosa	Black	30+
Thobeka	Mother	Edu-care	isiXhosa	isiXhosa	Black	60+
Zimkhitha	Care worker	Edu-care	isiXhosa	isiXhosa	Black	40+
Lulama	Care worker	Edu-care	isiXhosa	isiXhosa	Black	50+
Esihle	Mother, Care worker	Edu-care	isiXhosa	isiXhosa	Black	30+
Funeka	Mother	Edu-care	isiXhosa	isiXhosa	Black	40+
Gloria	Care worker	Orphanage	isiXhosa	English	Black	40+
Boniswa	Sibling, Care worker	Orphanage	isiXhosa	English	Black	30+
Nobantu	Mother, Coordinator	Orphanage	isiXhosa	English	Black	60+
Mthetheleli	Father, Care worker	Orphanage	isiXhosa	isiXhosa	Black	60+
Veliswa	Mother, Coordinator	Orphanage, Pre-school <sup>c</sup>	isiXhosa	isiXhosa	Black	40+
Nomlanga	Care worker	Orphanage	isiXhosa	isiXhosa	Black	30+
Nobuhle	Care worker	Orphanage	isiXhosa	isiXhosa	Black	30+

<sup>a</sup> Caregiving role refers to participants' primary role in caring for children with disabilities. <sup>b</sup> Associated centre refers to the DICAG-affiliated centre where participants worked, attended support meetings, and/or participated in the research project (since some participants neither worked nor attended meetings at a centre). <sup>c</sup> Two of the participants ran their own pre-schools, but came to one of the centres to participate in the study. <sup>d</sup> Language choice refers to the predominant language which participants chose to speak during the interviews. Despite this, most participants code-switched between languages to varying degrees during the interviews.

Table 2

*Participants' Child/Sibling Roles, Age and Disability of Child/Sibling*

Pseudonym	Child/Sibling Role <sup>a</sup>	Age of Child/Sibling <sup>b</sup>	Child/Sibling Disability <sup>c</sup>
Rachel	Son	30 years	Intellectual disability, multiple disabilities
Giselle	Son	7 years	Down syndrome
Robyn	Son	5 years	Seizures, developmental delays, multiple disabilities
Jacqui	Daughter	22 years	Brain damage, multiple disabilities
Mandisa	Daughter	29 years	Disability
Nozuko	Son	-	Disability
Thembi	Sibling	12, deceased	Cerebral Palsy
Pamela	Son	12, deceased	Cerebral Palsy
Nandipha	Son	16 years	Brain damage
Nozibele			
Ndiliswa			
Thobeka	Son	23 years	Disability
Zimkhitha			
Lulama			
Esihle	Son	>2 years	Deaf
Funeka	Son	>5 years	Visual impairment
Gloria			
Boniswa	Brother	28, deceased	Intellectual disability, Epilepsy
Nobantu	Son	28, deceased	Intellectual disability, Epilepsy
Mthetheleli	Son	28, deceased	Intellectual disability, Epilepsy
Veliswa	Daughter	24 years	Epilepsy
Nomlanga			
Nobuhle			

<sup>a</sup> Child/sibling role refers to the relationship between the child/sibling and the participant. <sup>b</sup> Age of child/sibling refers to the age in years of the participant's child/sibling with a disability, or the age in years of the child/sibling when he/she passed away, according to the participant. One participant did not mention her child's age, and two others only referred to early points in their children's lives, so their exact ages are unknown. <sup>c</sup> Child/sibling disability refers to the disability/impairment of the child or sibling of the participant, according to information spontaneously provided by the participant about his/her child/sibling. In some cases participants described their children as having a disability, and did not provide more detail about this.

## **Language Practicalities and Concerns**

### **Document translations.**

Prior to collecting data, I gave some thought to potential language issues which I might face. After enquiring with Ms Ambrose and Ms Vuka, I discovered that the caregivers at the centres speak one or more of the following languages: isiXhosa, Afrikaans and English. I wanted all the caregivers to be able to access information about the study in their first language. Therefore, with assistance from isiXhosa and Afrikaans translators, I had the English versions of the briefing document mentioned above, as well as the informed consent form, translated into Afrikaans and isiXhosa. After developing an interview schedule as a guide for the semi-structured interviews, I also asked translators to develop Afrikaans and isiXhosa versions of the interview schedule. For both of these documents I asked postgraduate psychology students to do the translation work. The ethics committee required that research project documents in languages other than English or Afrikaans, in this case isiXhosa, be edited by a suitably qualified professional. I therefore gave the isiXhosa documents to a professor of African languages, and requested that she edit the documents, which she did.

### **Interpreter accompaniment.**

I also wanted participants to give participants the option to speak in the language(s) of their choice during interviews, to put them at ease, and to enable them to express themselves best, which would hopefully elicit richer descriptions of their experiences and aid in a more thorough answer to my research question. English is my first language, and I can speak moderate Afrikaans, but am unable to communicate in isiXhosa. Therefore, I employed an interpreter to accompany me on all the visits to the centres. The interpreter is a black South African woman in her mid-twenties, fluent in isiXhosa and English, who has a bachelor's level degree in a psychology, experience in transcription, and some volunteer experience working with another disability organisation.

As a part of preparing for having the interpreter as a part of my research team, I sent the interpreter the research proposal, informed consent document, and interview schedule, including the

isiXhosa versions of the latter two, for her to familiarise herself with the project, including the language and terms we might use in the interviews. Thereafter I met with the interpreter in person to discuss the aims and purpose of the study, each of our roles in the research process, and logistics with data collection. I also asked the interpreter about any feedback or questions which she had after reading through the research proposal and other documents. We also reflected on our expectations of each other in the process, and the concerns which we had about the process of interpreting. In addition, I emphasised to the interpreter that I wanted to put the participants at ease as much as possible, and wanted us a team to try to make the atmosphere during interviews conducive to the participants telling their stories. The purpose of this meetings was to clarify each of our purposes and methods for during the interviews and focus groups, to help us understand each other better, and to build trust between us (Brisset, Leanza, & Laforest, 2013).

I was aware that we might encounter issues in the interpreting process, logistically and relationally. Foremost I was aware of the power dynamics that might be in play in my relationship with the interpreter. Being a white, middle-class woman with a postgraduate degree, I was in already in a position of power because of my privileges in South African society. In terms of our roles in the research process, as the primary investigator I had a position of power in our relationships, including being the primary decision-maker about many aspects of the project, as well as being the interpreter's employer. At the same time, during data collection, the interpreter often holds a lot of power in what is communicated and how this is done, and therefore hold a position of power in this way, although institutions often ascribe very little power and low status to interpreters (Brisset et al., 2013). This interpreter was also a first language isiXhosa speaker, and therefore an expert in that domain in comparison to my being unable to speak or understand isiXhosa.

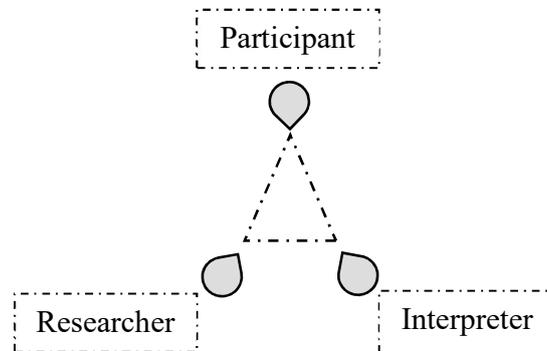
According to Brisset et al.'s (2013) systematic review, interpreters in the health care field often find it difficult to manage their roles, as well as the expectations which practitioners and patients have of them. Interpreters may face challenging situations in which the most ethical choice may be unclear,

such as when and if to use the interpreter's own insight or perspective to rephrase or reword during interpreting, or when and if to refrain from interpreting an utterance which was not intended to be understood by another (Brisset et al., 2013). These potential difficulties in interpreting, as well as how power dynamics play out during the research process, are important relationally as well as for effectively answering the research question.

Therefore, because I wanted to engage respectfully and effectively with the interpreter and the research participants, I made an effort to foster an open relationship with the interpreter, setting the tone from our first meeting. Thereafter, when we travelled together to and from the centres for data collection, we prepared on the way there by reflecting on how we felt about the upcoming visit, and any concerns we had. On the way back we debriefed about the visit, and reflected on how we felt and what we thought after the visits, including things we should repeat or do differently to be more respectfully and effective in our data collection. When we visited the centres, we introduced ourselves as a research team, with me as the primary investigator and her as the interpreter. When we conducted the interviews, I positioned the chairs so that the interpreter and I sat on the two close corners of an isosceles triangle, with the participant at the point further away. The aim of this was to enhance the sense in the room of the interpreter and myself as a research team. This also made it easier for the participant to switch between making eye-contact with me and with the interpreter, which was helpful for fostering the relationship and trust between the participant, myself, and the interpreter. By sitting at slight angles, we were also able to have some eye-contact between myself and the interpreter, which was helpful when needing to make non-verbal cues. Figure 2 shows the general shape of the arrangement during interviews.

Figure 2

*Diagram of positioning of researcher, interpreter, and participant during interview*



While I realise that my efforts to build and maintain a respectful relationship with the interpreter did not eradicate the power dynamics or some of the difficulties, it did feel like at the least we were able to be an effective team while collecting data, while respecting each other. Also, there is of course another side to this story, which is the perspective of the interpreter about what this process was like for her. I hope to write a joint paper with the interpreter about both of our experiences in this project in future. The interpreter was also involved in the transcription and translation process, which was difficult at times, but I describe this in more detail in the data analysis section.

### **Data Collection**

The primary form of data collection comprised semi-structured interviews with caregivers of children with disabilities at the DICAG-affiliated centres. I also conducted focus groups with the participants some weeks after the interviews, but this was more for the purpose of member-checking than generating new data. Here I describe the development and piloting of the semi-structured interview schedule, followed by the process of visiting centres to conduct the interviews and focus groups.

### **Semi-structured interview schedule.**

I decided to use a semi-structure interview approach for collecting data from caregivers about their experiences. This approach enabled me to use an interview schedule as a guide, rather than a set-in-stone protocol, for conversing with participants (Eatough & Smith, 2008). Conducting semi-structured interviews thus allowed me some flexibility during the interviews, so that I could pursue new or interesting topics which participants brought up that I had not thought of beforehand (Smith & Osborn, 2003). Using a semi-structured interview format also facilitated establishing rapport with the participants, and eliciting richer responses from participants, as I could probe participant answers and follow issues of their concern during the interview (Smith & Osborn, 2003). While valuable, the flexibility of this approach presented me with the challenges of balancing when and how to focus the interview with the schedule, and when and how to follow and probe the participants' responses (Eatough & Smith, 2008). In addition, analysing the transcripts from semi-structured interviews tends to be more difficult than from structured interviews (Smith & Osborn, 2003). In spite of these challenges associated with the approach, employing a semi-structured approach during interviews was important for me, because I wanted to give the participants as much freedom as possible to tell their stories (Flick, 2009; Smith & Osborn, 2003).

I developed the interview schedule by gleaning from themes about caregivers' experiences in the literature and from interview schedules developed by researchers in related studies, by brainstorming, and by consulting with my supervisor. After generating lists of relevant topics, I created questions related to each topic, and potential follow up probes and prompts (Smith & Osborn, 2003). As Parker (2005) suggests, I tried to frame questions in an open-ended way as much as possible, attempting to avoid steering participants too strongly towards particular responses. To this end, I also tried to frame questions in a neutral way, rather than asking leading questions (Smith & Osborn, 2003). I also endeavoured to introduce topics to participants with more general questions, and then move

towards more specific areas, with more or less prompting, depending on the responsiveness of the participants (Smith & Osborn, 2003)

Developing the interview questions beforehand helped me to think about the topics that might be covered in the interviews, including potentially sensitive topics and how I might deal with these (Smith & Osborn, 2003). In addition, this process helped me to think about appropriate wording to use for questions, particularly with regards to avoiding the use of psychological jargon, and making the questions easy to understand (Smith & Osborn, 2003). The interview schedule was also translated into Afrikaans and isiXhosa, for reference when the interpreter and I spoke these languages during the interviews. Because my Afrikaans is limited, the interview schedule was particularly helpful for me for familiarising myself with the Afrikaans vocabulary of the topic in preparation, as well as assisting me with prompting during the interviews. The English, Afrikaans, and isiXhosa versions of the semi-structured interview schedules are presented in Appendices I, J, and K respectively.

#### **Pilot: Testing the interview schedule.**

To test the interview questions, practice my semi-structured interviewing skills, and gain insight for improving the interview process, I conducted a pilot interview with a caregiver of a child with a disability (Silverman, 2013). This caregiver, Rachel, was involved in DICAG, and had this in common with the participants. In addition, as a part of her involvement in DICAG she had interacted with many other caregivers of children with disabilities. Lastly, my supervisor and I knew that Rachel had told stories about her caregiving experiences before, and had had opportunities to process these, so would probably be a somewhat less vulnerable person to conduct the pilot interview with. This combination of factors meant that we felt Rachel was an appropriate person to pilot the interview schedule with.

When I interviewed Rachel for the pilot, I informed her that part of the purpose of the interview was for me to learn how I could improve the interview process for the research project. I asked Rachel to tell me during and after the interview when, if or how my questions, comments, or approach could be better done differently. The pilot participant reflected that there was not any constructive criticism

which she could give, and said she felt that the questions I asked, and the atmosphere of warmth and respect, would be conducive for collecting data from the other participants. Although I did not initially plan to analyse the pilot participant's responses, the participant requested that I report on some of the issues she mentioned, and after the interview I decided that it would be valuable and appropriate to include data from her interview in the analysis.

### **Arrival at the centres.**

I visited each of the centres twice in order to interview all the participants, and once for conducting the focus groups. On each visit, I picked up the interpreter and then Ms Vuka, and drove the three of us to the centre. During the car rides we would prepare for the visit by discussing its purpose, and any concerns we had about the visit. I always brought with tea, coffee, sugar, milk, biscuits, and fruit, and on focus group days, lunch, for us and the participants. Upon arriving at each centre for the first time, Ms Vuka introduced me and the interpreter to the centre coordinators. While making tea and coffee for everyone, we discussed logistics for the day, such as where the interviews or focus groups would take place, and who would be interviewed when. As far as possible, we tried to conduct interviews and focus groups in quiet rooms which would have the fewest interruptions possible. Factors influencing the order of participant interviews included when certain participants had to leave or had other commitments at the centres, participant preference, centre-coordinator preference, and the age or status of the participants at the centre.

At each centre, I asked all the caregivers to gather in a group before the interviews started. I then invited the caregivers to participate, and explained all the information in the informed consent, with the help of the interpreter at the centres where participants spoke isiXhosa. I checked with caregivers if they had any questions, and informed them about the logistics of the upcoming interviews and focus groups. I also handed out copies of the informed consent documents for participants to keep, and asked those willing to participate to sign copies of the informed consent documents for me to keep. I explained the informed consent in these group settings to conserve time, and aid in my not rushing

through this important step in data collection. In a few cases, individuals were not able to be present during these group discussions, in which cases I explained the informed consent to them individually.

### **Individual interviews.**

Before beginning each individual interview, I arranged the furniture and other objects such as toys in the interview rooms to make space for three chairs for myself, the interpreter and the participant. When a participant arrived, I thanked them for their willingness to participate, and gave them a thank you blanket, which they could choose from a selection of different colours and designs. When participants had travelled to the centre especially for the interview, I also gave them money for transport. Participants had to sign for both of these, so that I could keep a record for funders. Most participants expressed joy and gratitude when receiving the blankets, and many thanked me and the interpreter again at the end of the interview. After giving participants the blankets, we all sat down, and the interpreter and I reintroduced ourselves, and very briefly restated the purpose of the study. Thereafter I told the participants that we would start the recording, did so, and began the interviews.

I started by asking the participant which language or languages he or she would like to speak during the interview. With participants whose first language was Afrikaans, the interpreter did not join us during the interview. With participants whose first language was isiXhosa, the interpreter joined us during the interview, regardless of how much isiXhosa the participant chose to speak, so that the participant always had the option to switch to isiXhosa should they wish. Besides the pilot participant, all participants whose first language was Afrikaans chose to speak Afrikaans during the interview. With the other participants whose first language was isiXhosa, the languages chosen ranged from speaking entirely English, a mixture of varying proportions, and speaking entirely isiXhosa during the interview.

When participants spoke isiXhosa, the interpreter interpreted into English so that I could understand. As per our discussion beforehand between the interpreter, myself and the participant, the interpreter tried to interpret every few sentences, so that there was not too much back log for the interpreter to remember. Sometimes, however, this was difficult when participants were very

enthusiastic about telling a story, and either we or they did not want them to stop their flow. Because I planned to transcribe and translate the interviews afterwards, I conveyed to the interpreter that she did not need to worry if interpreting during the interview was not exact, as participants' spoken words would be transcribed and translated later. Rather, I emphasised the importance of communicating the gist of what was said- in however much detail the interpreter could manage- to enhance the flow of the interview, and enable communication between myself and the participant.

I started the interviews by asking participants about a usual day in their life. I used the interview schedule as a guide to explore participants' experiences of being caregivers of children with disabilities. We covered topics relating to their every-day routines, their relationships with the children in their care, their families and broader communities, their needs as caregivers, and others. Participants told me stories about their experiences, and expressed their attitudes, thoughts and feelings. Sometimes during the interviews participants became emotional. At the end of interviews, I always asked participants if there was anything else they would like to tell us, and this often elicited more stories. I also always asked if participants would like to ask me or the interpreter anything, which they occasionally did. Afterwards, I always thanked the participant, and reminded them that they could contact me should they have any questions or decide they would like help accessing psychological report after the interview.

I felt like the interpreter and I were able to establish good rapport with participants. Participants opened up during the interviews, and shared personal stories about their caregiving experiences. Many participants also expressed gratitude for the opportunity to talk to us. Throughout the interviews, I tried to be caring and respectful towards participants. I tried to balance being sensitive to the participants' emotional state, their body language and what they were saying, while also gently guiding the interview to answer the research question, and keeping in mind the presence and contributions of the interpreter. As such, conducting the interviews was quite exhausting for me and the interpreter, and we often commented on this when we debriefed on the way home.

**Focus groups.**

After conducting the interviews, I started listening to the audio and making some notes about prominent themes. I arranged the dates for the focus groups at the centres. The purpose of the focus groups was for me to discuss my preliminary interpretations of the findings with the participants, and engage with them regarding their viewpoints. Providing opportunity for participants to comment about the qualitative findings of a study in this way is called member checking, and is one strategy for evaluating the validity of the findings (Creswell, 2014). I also used the focus groups as an opportunity for closure with participants; I brought lunch and snacks, and in addition to debriefing with participants about their experiences of being interviewed, I reiterated my gratitude for their participation, and told them when they could expect their centres to receive the report from me with the findings.

**Data Analysis**

The data which I analysed to answer the research question comprised all 23 individual interview transcripts, translated into English where necessary. For the purpose of this project, I did not analyse utterances spoken by the interpreter or myself, but rather analysed the utterances of the participants. The exception to this was where I made process notes about dynamics between myself, the participants, and the interpreter. I did not finely analyse the focus groups either, but used them as a method of member checking.

**Preparing and processing data for analysis**

***Transcription and translation.*** The data I collected comprised audio recordings of interviews and focus groups. Because I wanted to analyse the data by engaging with it in text form, I needed to organise transcription of the audio. The audio recordings consisted of speech in English, Afrikaans and isiXhosa. Once transcribed, I wanted to analyse the data in English, and therefore needed to have the Afrikaans and isiXhosa transcription text translated into English. I employed individuals and a company to assist with the transcriptions and translations. To each transcriber and translator, I sent instructions about the approach to transcription and translation.

The postgraduate student who had assisted me with translating the informed consent document and interview schedule- and was therefore familiar with the project- transcribed and translated the Afrikaans audio recordings. I employed the interpreter who accompanied me during data collection to transcribe and translate the isiXhosa audio recordings. I felt that because of her familiarity with the project and participants, her presence during all the isiXhosa interviews, and her transcription experience with an official organisation, she would be a suitable person to assist with these tasks. I transcribed some of the English audio, and asked another postgraduate student with experience transcribing for the psychology department to transcribe the remainder of the English audio.

***Checking transcriptions and translations.*** I put in place quality checks during the preparation of the data for analysis. While I hoped this might be a ticking-the-box routine, checking the transcripts and translations yielded multiple issues. Dealing with incomplete and inaccurate transcripts and translations added considerably to the time it took to prepare the data for analysis. Details of this process are presented in Appendix L.

***Additional editing.*** A final aspect of editing the transcriptions and translations involved changing the real names of people, places and organisations in the transcriptions to protect the identity of participants, with the exception of the organisation of DICAG, because the role of this particular organisation in the lives of the participants was relevant for the overall purpose of the project.

#### **First layer: Thematic analysis.**

I chose to use thematic analysis as a first layer to make sense of the data, as I felt it would be a fitting method of analysis for this project. Thematic analysis has the advantages that researchers from a variety of theoretical vantage points can employ it, it can be used to highlight contrasts as well as similarities across data, it does not constrain findings to a set framework and can therefore be used to find unexpected results, and it can be useful for informing policy development (Braun & Clarke, 2006). Braun and Clarke (2006) also argue that thematic analysis is a useful approach to use when

collaborating with research participants, and thus is a fitting approach for this study, as I discussed some of the themes from the interviews with the participants during the focus groups.

In preparation for thematically analysing the data, I prepared and processed the raw interview and focus group audio data into English transcripts. Thereafter, I followed Braun and Clarke's (2006) *Using Thematic Analysis in Psychology* method of analysis, which incorporates familiarising oneself with the data, generating initial codes, grouping the codes into related themes, organising the themes into a logical network, and analysing and naming the themes in a meaningful way. In addition, I drew from Saldana's (2009) *Coding Manual for Qualitative Researchers* to assist me with the process of coding, as it contains much more detail about coding processes than Braun and Clarke's (2006) guidelines. I used a computer assisted qualitative data analysis software (CAQDAS) programme, Atlas.ti (Version 7.5.15; 2016), to assist me with organising and analysing the data. Like most other CAQDAS programmes, apart from a limited *auto-code* function which I did not use, Atlas.ti does not code or analyse the data, but is useful for organising and managing data efficiently to facilitate human analysis (Saldana, 2009). As Saldana (2009) recommends, I attempted to be organised throughout the data analysis process, by saving multiple backups of all the project data, and systematically labelling files to keep track of the many different documents.

#### ***Preparing and processing data for analysis.***

Being organised and keeping track of different versions of interview transcripts was particularly important while I prepared the data for analysis.

#### ***Familiarising myself with the data.***

Because I conducted the interviews myself, I had the advantage of already having some familiarity with the interview data before commencing analysis. My roles in preparing the data for analysis, which included transcribing some interviews, and checking and editing many of transcripts helped me to become familiar with the data. As I read through the interview transcripts in preparation for coding, memories of the centres, the participants, what was said during interviews, and the

emotional responses in myself and in the participants helped me to focus, connect, and remember more about the data I collected during interviews.

### ***Generating initial codes.***

In qualitative analysis, a code can be defined as label that captures some content or essence of a portion of data (Saldana, 2009). The ways in which different researchers assign codes to data vary widely. A researcher's theoretical framework and personal involvement with participants during data collection can influence the coding methods which a researcher chooses, and the particular codes a researcher assigns to portions of data (Saldana, 2009). Sipe and Ghiso (2004) highlight that when researchers analyse and interpret qualitative data, we always bring some of our own subjectivities into the process, including in the ways we generate and assign codes to data. To keep focussed and work productively during analysis, Saldana (2009) emphasises that researchers should keep in mind the purpose of their research question when choosing coding methods and carrying out coding processes. My purpose was to explore the experiences of caregivers of children with disabilities. I wanted my method of analysis to allow me to be surprised by aspects of caregivers' experiences. Therefore, rather than starting coding by fitting data extracts into an existing framework, I chose to employ an open coding approach, generating and assigning codes as I systematically worked through all of the interview transcripts, attempting to give equal and thorough attention to all of the data (Braun & Clarke, 2006). As I created and assigned codes to the transcripts using Atlas.ti, the programme automatically kept a record of all the codes and associated data extracts, creating a code list for me. This helped me to keep track of the codes throughout the analysis process.

While coding, I often applied multiple codes to single data extracts, a technique called simultaneous coding (Saldana, 2009). I also used embedded coding, in which I assigned codes to a shorter data extract within an already coded larger data extract (Saldana, 2009). In keeping with Braun and Clarke's (2006) guidelines, I tried to code the data inclusively, meaning that I kept some of the text surrounding each relevant idea in an extract, in order to give context to the extract later during analysis.

The types of codes which I assigned to data extracts included attribute codes, descriptive codes, in vivo codes, process codes, emotion and value codes, versus codes, evaluation codes, and research dynamics codes, descriptions of which follow. I have also included examples of some of the codes which I generated during initial coding, to give the reader a better idea of the process.

*Attribute codes.* When a researcher provides basic information about the type of data, time and setting of data collection, and participant demographic information about each data item in a standardised way, this can be called attribute coding (Saldana, 2009). What is helpful about attribute coding is that it provides information about the participants and context of each data item, which can assist with interpreting the data during analysis (Saldana, 2009). At the beginning of each transcript, I detailed the following attribute codes of each data item:

*date of interview; date of transcription; transcriber; interviewer; participant code and pseudonym; interpreter, if present; location of data collection; interview length.* With each transcript, I selected all the text and also assigned an attribute code indicating the participant's caregiving roles with respect to children with disabilities. These codes included *sister, mother, father, centre coordinator, and centre care worker*. Some participants had multiple caregiving roles, and were assigned multiple attribute codes accordingly. For example, the participant Nobantu was both a mother of a child with disability, as well as a centre coordinator of one of the data collection sites (see Table 1). Assigning attribute codes to each transcript meant that when looking at a particular quotation later during the analysis, I could always see the caregiving role of the participant whose quotation it was, which helped me to make sense of the quotation and other assigned codes.

*Descriptive codes.* Descriptive coding involves determining what topic a portion of data deals with, and assigning a code name which conveys this topic to the portion of data, giving the researcher an idea of the different topics in the data (Saldana, 2009). Examples of descriptive codes which I assigned to data extracts include *Transport issues, Centre needs, and Relationships with other carers*.

*In vivo codes.* In addition to descriptive coding, I also employed in vivo coding, whereby I assigned a code to a portion of data using the exact language of the participant as the code name (Saldana, 2009). Particularly when I struggled to conceptualise the essence of a portion of data in my own words, I used an in vivo code to label it. In vivo coding was also helpful when I felt like a short excerpt of a participant's speech captured the essence of that experience so well, that their words were the most useful label I could assign. For example, the phrase *You must just accept it* was repeated by multiple participants, and I assigned this code to each instance when participants seemed to be communicating the view that, well, *You must just accept it*, when you have a child with a disability.

*Process codes.* Codes which refer to actions in the data can be called process codes, and are named using the gerund form of the verb denoting the action (Saldana, 2009). Process codes might refer to observable behaviours, such as crying, walking, or hitting, or to more conceptual actions such as struggling, adapting, or learning (Saldana, 2009). I found process codes useful for labelling actions which participants spoke about in their daily routines of caregiving, such as *feeding my child*, *changing nappies*, and *engaging with health professionals*. Process codes were also useful for coding other aspects of caregiving experiences such as *finding out about my child's disability* and *learning to care*.

*Emotion codes.* As an important aspect of human experience, I was also interested in the emotions which participants experienced as caregivers of children with disabilities. I used emotion codes to label emotional states which participants spoke about or which I inferred from their words, silence, and/or behaviour during the interview (Saldana, 2009). Emotion codes included *joy*, *anger*, *sadness*, and *shock*, amongst others. The potential overlap of emotion codes and process codes is a good example of why I employed simultaneous coding of the data: I felt that both the actions of a participant and their feelings during that action were important aspects of their experience, and wanted to be able to code a particular extract for both aspects of experience.

*Value codes.* Value codes can refer to what participants find important in life, their attitudes, and their beliefs (Saldana, 2009). While telling me about their caregiving experiences, participants spoke

about various beliefs, attitudes, and values which they or others held, and assigning value codes was helpful for categorising these data excerpts. For example, the belief that *God gives strength to endure*, and the attitude that *You must show your child love* were expressed by participants, and assigned value codes.

*Versus codes.* When a researcher perceives a direct conflict between two groups, phenomena, or ideas in the data, it can be useful to apply a versus code (Saldana, 2009). In this data, the most obvious seeming duality was the conflict between ideas about *normality versus difference* in participant's stories about caregiving for children with disabilities.

*Evaluation codes.* Participants' evaluations of organisational and institutional policies and programmes were important aspects of their experiences, and I coded these with evaluation codes. Examples of these include *DICAG workshops as helpful* and *Grant money not enough*. Understanding participant evaluation of policies and programmes can be useful for providing feedback to the policy and programme providers (Saldana, 2009). In the case of this research project, one of the aims was to support caregivers of children with disabilities, in part by exploring caregivers' needs and experiences of support from organisations such as DICAG and government, in order to provide motivation for further support by such institutions. Using evaluation codes was a useful way to categorise data pertaining to these experiences of participants.

*Research dynamics codes.* In addition to coding the content of what participants said, I also coded some data extracts with comments about dynamics between the participant, myself, and/or the interpreter. These research dynamics codes assisted me with reflecting on how I conducted the interviews, how the participant engaged, and the role of the interpreter as well. Although I did not include these codes in further analysis when generating themes, I used them in reflecting on the interview processes.

### ***Grouping codes into themes.***

After initial coding of all the data, I had generated just over a thousand codes. I knew that there was quite a lot of repetition in the concepts to which different codes referred, and that I would be able to meaningfully consolidate the initial codes into groups of similar or related codes, to make further analysis more manageable (Saldana, 2009). Using the code list in Atlas.ti, I sifted through all the initial codes, and grouped them into families of similar or related codes. Throughout the process of initial coding and consolidating similar and related codes, I often thought of new meaningful ways to categorise data extracts or group related codes into themes, and assigned codes to data extracts and themes accordingly (Braun & Clarke, 2006). Grouping the initial codes in these ways yielded about one hundred code families, or themes. Like the initial codes, some themes still referred to varying and potentially overlapping aspects of participants' experiences, such actions, emotions, and values, while other themes comprised different conceptualisations of the data, such as *Motivations for caring*, *Boundaries and discipline in caring*, and *Responsibility for caring*. These themes were still quite disorganised, and differed in their specificity. Some would be better suited as sub-themes, and others as main themes, and still others might not be included in the analysis at all (Braun & Clarke, 2006).

### ***Organising themes logically and meaningfully.***

During the process of grouping codes into themes, I began to brainstorm ideas about which conceptualisations of the data would be most meaningful for presenting the findings of the research project. I thought about how the different themes related to each other, and different ways of organising the themes, and created mind maps and lists in different colours to explore these options (Braun & Clarke, 2006). For example, I considered grouping the findings similarly to how I organised the literature review, by focusing on different domains of caregivers' experiences, such as *Cognitive components of caring*, *Emotional experiences as a caregiver*, *Caregiving and social dynamics* and *Experiences of accessing resources*. I also wondered if presenting participants' experiences as

caregivers in the contexts of different system levels—*micro*, *meso* and *macro*—might be a helpful way to organise the findings from the study.

### **Second layer: Tronto's (1993) conceptualisation of care.**

As I grouped and regrouped codes and themes, I found myself thinking about how the codes and themes linked to the theoretical framework of an ethics of care. For example, many of the codes and themes from the transcripts linked to ideas about who takes responsibility for caring, and details about what the labour of care. I found that the language of an ethics of care seemed to be one helpful way of making sense of participants' experiences as I interpreted them in the transcripts. I created more mind maps and mentally checked how my existing themes and codes might fit into a thematic map based on an ethics of care framework (Braun & Clarke, 2006).

Finally, I decided to organise the findings about caregivers' experiences using Tronto's (1993) conceptualisation of care as a framework. I felt that the framework fit well with the stories the caregivers told during interviews, and that this framework provided a meaningful structure around which to discuss caregivers' experiences (Braun & Clarke, 2006). I reorganised the existing themes into this framework. In the next chapter I discuss the findings from this analysis accordingly.

### **Efforts Towards Trustworthiness**

In efforts to develop the trustworthiness and credibility of the findings, I employed a number of strategies. For example, I attempted to be self-reflexive and transparent when describing the research process, including difficulties I experienced along the way, and details about data collection and analysis (Tracy, 2010). In addition, by providing descriptions of the context of the research and the participants, I hope to have given the reader an idea of the plausibility of the findings presented in the next chapter, as well as relevance of the research in various contexts (Creswell, 2014; Tracy, 2010). After my preliminary analysis of the interviews, I met with participants to discuss the prominent themes in focus groups. This provided a form of member checking, in which I checked the accuracy of the findings with the participants (Creswell, 2014; Saldana, 2009). In the focus groups, participants

engaged enthusiastically about the topics, and seemed to communicate agreement with the importance of the themes we discussed. In addition, my supervisor provided a form of auditing, by checking my coding and organisation of the codes into themes, and offering helpful comments which I incorporated into the analysis (Barker, Pistrang, & Elliott, 2002). After completing the analysis, I also checked through the initial codes and themes to ensure that no important data was excluded from the findings. Finally, to enhance credibility of the findings, in the following chapter I tried to *show* rather than just *tell* the reader about participants' experiences, by providing thick descriptions of the contexts and contents of excerpts from participants' interviews (Tracy, 2010).

Having discussed the method of data analysis, I will present the findings in the following chapter.

## Chapter 5: Findings

Having collected data by conducting interviews with caregivers at the centres, and having used thematic analysis and Tronto's (1993) conceptualisation of care as tools for analysing the data as outlined in Chapter 4, here I present my understanding of these caregivers' experiences, in attempt to answer the research question: What are the experiences of caregivers of children with disabilities at DICAG-affiliated centres in the Western Cape, South Africa?

To familiarise the reader with the framework for analysis, I first review Tronto's (1993) conceptualisation of care. Thereafter I present participant accounts of their experiences as caregivers, organised using Tronto's (1993) care framework, and divided into smaller sub-themes.

### Tronto's (1993) Care as Four Stages of Practices and Virtues

As discussed in Chapter 3, and reviewed here for the reader's ease of reference, the four phases of care according to Tronto (1993) are as follows:

1. **Caring about**, the practice of recognising a need for care, is the first phase of care. This recognition of a need requires the virtue of **attentiveness**, as one cannot recognise a need without being attentive (Tronto, 1993).
2. The second phase of care is **taking care**, which involves the practice of assuming responsibility for a need that was noticed in the first phase. This practice involves moving from being aware of the need, to taking **responsibility** for how to address the need. The associated virtue with this action is responsibility (Tronto, 1993).
3. **Caregiving** is the third phase of care, which encompasses the actual, hands-on work of attending to needs; in other words, the labour of care. The necessary accompanying virtue to caregiving is **competence**, as a need will only be met if the caregiver has the skills to meet the need (Tronto, 1993).
4. The fourth phase of care involves the **recipient of care**. The associated virtue is **responsiveness**. An act of care is only complete when the recipient responds in some way,

whether verbally, in behaviour or in some other way, to indicate that their needs have been recognised, taken responsibility for, and competently met (Tronto, 1993).

For ease of readability, from here on I will not cite Tronto (1993) with every reference to these phases of care, but the reader can assume I am referring to Tronto's conceptualisation of the terms unless otherwise specified.

#### **Four Stages of Caring Linked to Participant Experiences**

Comprising these four stages of care as practices and associated virtues, Tronto's (1993) conceptualisation of care provided a fitting framework around which to discuss participants' experiences. Employing this framework brought attention to participants' experiences of who is attentive to whose and which needs, who takes responsibility for caring for whom and how, how the labour of care is distributed and carried out, and how receivers of care are involved with and respond to the care which is offered to them.

As I discuss participants' experiences associated with these different stages of caring for children with disabilities—caring about and being attentive; taking care and being responsible; caregiving and being competent; care-receiving and being responsive—I describe associated aspects of participants' experiences such as emotional responses, attitudes, challenges, coping mechanisms and how participants engage with others in their lives, such as their families, friends, colleagues, communities, institutions such as centres, schools, churches and health facilities, organisations such as DICAG, and the South African government.

It may be helpful for the reader to keep in mind that this conceptualisation of the themes from this study means that some stories from participants are artificially dissected and discussed in different sections. Accordingly, similar quotations may be presented in different sections, depending on which elements of care or experiences they highlight best. In addition, the combination of the variance in the length of the interviews, and the element that some participants were more articulate than others, meant that there are more excerpts from some participants' interviews than others.

Many of the excerpts from the transcripts are English translations of participants' original utterances which were in either Afrikaans or isiXhosa. So that the reader is aware of when excerpts are translated accounts, I left the translated quotations in italics, as they appeared in the transcripts.

When presenting excerpts of participants, I included the caregiving role of the speaker, such as care worker at a centre or mother of a child with a disability, to provide context about who is speaking. All names in excerpts are pseudonyms, to protect participants' and others' identities. For improved readability, participants referred to as a mother, father, or sibling denote a mother, father, or sibling *of a child with a disability*, unless otherwise specified. Similarly, usage of *daughter, son, child* or *children* refer to such individuals *who have a disability*, unless otherwise specified. Should the reader wish to reference more information about participants and their child or sibling with a disability to provide further context for the quotations, it may be helpful to review Tables 1 and 2 in Chapter 4 about participant and child/sibling characteristics.

### **1. Caring about, being attentive.**

The theme of caregivers' caring about and being attentive to the needs of children with disabilities comprised three main subthemes: stories about first engagements when caregivers first learned about children's disabilities; caregivers' accounts of the value of attentiveness when caring for children with disabilities; and tales about how caregivers prioritise the needs of children with disabilities.

#### ***Beginning to care about: First awareness of children's needs, and finding out about children's disabilities.***

Both parents and care workers at the centres told stories about when they first engaged with children with disabilities, and/or became aware of their disabilities. For the parent caregivers, noticing and being attentive to the needs of children with disabilities began within the first few years after the child's birth, and for centre care workers, upon beginning working at the centres, or helping to care for another's child with a disability. In their accounts of their first engagements with children with

disabilities, participants spoke about four main facets of their experiences: their expectations and emotional responses; their confrontations with children's dependencies; experiences of uncertainty and not understanding; and ways of finding meaning and accepting the child's condition.

*Expectations and emotional responses*

In the interviews, participants spoke about some of the emotions which they experienced when finding out about their children's disabilities, such as shock, distress and fear. Rachel, a mother, spoke about her expectations of an ongoing hope for a healthy baby, and the shock she experienced finding out about her son's disabilities:

I can remember going home so devastated that, even though I knew in the back of my mind, that somebody maybe say- you still hope that this child is fine ... because it's a shock for you, when you give birth to a child with a disability. ... you know, because you expect a healthy baby- everybody when they pregnant they...check for ten fingers and ten toes and then you see: okay the fingers and everything is there, and you know? You- you- I think when you give birth you you you automatically look at your child and say: ooh this child is everything is fine. You know?

Rachel was the only caregiver who explicitly spoke about her expectations and hopes that her baby would be healthy. The shock and feelings of being heartbroken that some other caregivers described suggest that they may also have expected healthy, non-disabled children, although they did not articulate their expectations during the interviews. A mother of a son with Down syndrome, Giselle, recalled the shock she experienced, and how her emotional reaction to finding out about her son's condition inhibited her from asking the doctor for more information:

*At that time the doctor wanted to tell me what Down syndrome entails, but I had too big a fright when they told me I had a child with Down syndrome. I told the doctor that I didn't want to hear about it any further. Because I cried too much and I never visited anyone again to ask. I*

*wasn't really, I should've asked him, but I didn't ask him about the meaning of having Down syndrome.*<sup>2</sup>

Another mother, Mandisa, whose daughter was diagnosed a few years after her birth, described how she felt heartbroken when she found out about her daughter's disability:

*I gave birth to an able-bodied child, she was diagnosed at the age of four. ... I was very heartbroken when my daughter got disabled because she's the only girl among other children I have.*

Two caregivers who worked at the orphanage spoke about how afraid they felt when they were first confronted with attending to the needs of children at the centre. In response to a question about how she felt when she first arrived at the orphanage, Nobuhle said,

*Yho I felt hurt, it was painful... At first I was scared of them, I felt like I'm not caring for them the right way.*

Nomlanga recounted how anxious she felt about caring for children when she first came to work at the orphanage:

*Even when I was going to bath a child, I used to shake... I was really worried, kept thinking that I might break the child.*

Nandipha, a mother, recounted feeling a mixture of emotions around the time of finding out about her child's condition. During the time when her child was in hospital and doctors were trying to figure out what was wrong with her child, Nandipha described feeling as follows:

*When I took him home from the hospital he had no complications, but when we woke up the next morning his head was swollen and his eyes were closed. I took him to the General hospital, when I got there they said he has a brain damage. They did not know what happened, but what they know is that he bled. He was in a coma for 5 months ... Yho it was bad. It was really bad,*

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<sup>2</sup> As a reminder to the reader, quotations presented in italics indicate that these quotations have been translated into English from either Afrikaans or isiXhosa. In contrast, quotations in plain text were originally spoken in English.

*most of the time I would pray, and I also cried a lot because I did not know what will happen next...*

When her child came out of the coma and she could finally take her child home from the hospital, she expressed feeling so happy:

*I was very happy the day the doctor said we can go home, I was so happy ...they examined him and told me that he is fine but he will stay the way he is, he won't be able to do anything... I am just thankful that he is alive.*

*Messages about children's dependency*

As Nandipha's story alludes to, many other mothers spoke about their experiences with doctors and other health professionals around the time of their child's diagnosis. What stood out for some of the mothers was the doctor's emphasis on what their child would not be able to do. Nandipha also spoke about how the doctors told her that her son would not be able to do many things:

*They did not know what happened, but what they know is that he bled.... He was in a coma for 5 months, his doctor said he will not make it.... So I stayed in [the hospital], and kept on praying because I didn't know what will happen next after the doctor said he will not make it.... Whether they will switch off the machine because the child won't survive. And even if he makes it he won't be able to do anything. He won't be able to speak, to see, or to hear, he just won't be able to do anything...*

In the following excerpt, Rachel described her experiences with the doctors informing her of her son's diagnosis:

The doctor just said he is mentally disabled, they still used the term handicapped. They said he is handicapped and I asked them what is handicapped, he said, "No, he wouldn't be able to walk, he wouldn't be able to talk". The doctor wasn't like looking into your eyes, he was just like, "He wouldn't be able to walk and he wouldn't be able to talk". You know all the, "won't be able"s. And you know that also sort of de-motivates you because it is a negative report that

he is giving to you, but he is not really compassionate. ... But no, he is just like saying that, “He won’t be able to,” because there is so many people that he still has to see.

*Uncertainty, not knowing what to do or what’s going on.*

Many of the participants described how they experienced uncertainty around the time of finding out about their child’s disability, which is evident in some of the aforementioned excerpts. Pamela, another mother who became involved with DICAG and started a care centre some years after her son’s birth, described her experience of not knowing what to do when her child with cerebral palsy was born:

I have a child with disability. When that child was born...before I joined DICAG, I didn’t know what to do and it was the first time I have a- I give birth to a child that who is a cerebral palsy child. I didn’t know what to do.

Funeka, also a mother, spoke about how frightened she felt, not knowing how she was going to cope, after she found out her child had a disability:

*To have a child with disability, is scary at first. You see. The first time he arrives you get frightened because you don't know how you are going to cope.*

*Making sense, accepting, and finding meaning.*

While telling stories about first encountering children’s disabilities, many participants described that despite difficulties, they had come to understand or make sense of the child’s condition in some way, learned to accept their child’s condition and find meaning in the situation. Some participants understood their child’s condition in terms of medical causes; some also believed that God had a role in their child’s condition. These ways of making sense of their child’s condition were not mutually exclusive for participants. For example, Robyn described her understanding of the medical causes of her son’s disability, and how she comes to terms with her son’s condition through believing he is a “gift from above”:

*He is not normal, so it is, it’s difficult and... In the beginning, it was very very difficult because it was my first child I didn’t understand what is going on, I ( ) didn't get clarity about*

*what is going on, but now at this moment when he is big I know (...) he is actually a gift from above, so it is not difficult anymore to understand. So he is actually a special child. ...*

*It is now only the the the uhm the fact that he uhm gets more fits, I don't understand it at all. But otherwise I understand completely well why he is so. It is because of jaundice that he is the way he is. So if he didn't have jaundice, he would've been normal. Yes if he didn't have jaundice he would've been normal, but otherwise it goes on.*

Giselle detailed how she had tried to make sense of her son's disability by asking the doctor questions:

*They said that his disability, I did ask if it is alcohol syndrome or is it (...) my age? Then they said, "No it's not an alcohol syndrome child, the child has little fingers and toes on the sides and feet, he is a normal Down syndrome child." I am just blessed as one of the parents who is over their age. Because I was forty-two when I had him. He is now seven years old and I'm now forty-nine. I was forty-two when I had him so he is a normal Down syndrome.*

Robyn's statement about it being easier to understand now that she views her son as "a gift from above" suggests a process of finding meaning and accepting her child's condition. Robyn's reference to her son as a gift from above links closely to the belief that a child is a gift from God, which many caregivers in the study articulated. Nozuko, a mother, expressed her belief that her child was a gift from God:

*Eh, at first, I didn't... but it's something you get used to when time goes, then you have to accept it. It's a gift from God. Then you have to live with that. ... It's the way that God created him.*

Like Nozuko, other caregivers articulated that they believed God had created their child the way their child was. When I asked Funeka, a mother, what she would say to another parent who had just found out about their child's disability, Funeka said,

*Ok just say to them God's gift and you see only Gods know sometimes why you see, just accept as your child. Nothing can do, say a child is a gift. Yes.*

For some mothers, the process of coming to terms with children's disabilities continued after initially finding out. Rachel described the first months and years after her son's birth:

Yes, you want to shout, shout, put your head in the pillow and shout! Because sometimes you feel like that, why has this happened to me? God, where were you? What are you doing you know? So shout if you want to shout. After you shouted, you will feel better later. You talk to somebody, you feel better. ... It was a daunting experience; it was an experience where I had to accept that he doesn't develop normal. I don't want to say 'normal' because at training we were trained not to say normal any more as a child with a disability. Ja, he didn't develop like—you had to, accept. I was angry, I was sad, I was crying a lot. You know, I was devastated and I was frustrated. You had all this mixed feelings, you know? But you eventually had to say to yourself that you have to accept that this is the road and you become better and you choose to become better.

The three previous excerpts from Rachel, Funeka and Nozuko contained phrases about the importance of caregivers accepting their children's conditions, and their situations. This theme of acceptance was very prominent in caregivers' stories. Ndiliswa, a care worker at the edu-care centre, articulated the importance of acceptance as follows:

First of all she is supposed to accept that child the way he is. She is supposed to accept that this child she's living with a disability so I suppose a...a...[changes to isiXhosa] *so she must understand that the child is disabled and accept his condition and train him accordingly.*

Two other caregivers, a sibling and a mother, felt so strongly about acceptance, that they believed if you didn't accept your child and his or her disability, God would give you another child with a disability. Boniswa, a sibling and a caregiver at the orphanage, posited that,

I told myself, if you don't like, if you don't like this child that God has given you, you gonna be pregnant another one. That was is also going to be disabled, until you accept the first one. If you don't accept the disability that God gave you- nobody wants a disabled child, nobody! But God

says ok fine, no matter you didn't have anything wrong in your pregnancy, but God will give it to you. You must just accept it.

Along similar lines, Pamela, a mother and centre coordinator, spoke about how she told other parents in her community to accept their children:

Then they are shy to go with that children out, then I took my child and showed them that, no, take your child out. That is a gift from God, if you don't accept your child who is going to accept it. Because what is going to happen if you don't accept this child? God is going to give you another disabled child. What are you going to do?

Mthetheleli, a father and care worker at the orphanage, also spoke about parents in his community who refused to accept that their child had a disability:

Yes, some parents are in denial. They don't want to accept that their child has a disability. When you try to bring into their attention, they just don't want to admit that their child has some form of impairment.

The excerpts presented thus far have illustrated some of the experiences of caregivers as they first became aware of their children's disabilities, or first interacted with children with disabilities at a centre.

#### *Attentiveness to children's needs.*

In the same way that first becoming aware of children's disabilities and needs for the first time was the first phase of care before taking responsibility and doing the labour of care, developing the virtue of attentiveness to notice children's needs on a daily basis was necessary in order to take responsibility and attend to those needs by doing the work of caring. Both parents and carers working at centres spoke about the importance of the virtue of attentiveness when caring for children.

*Attentiveness during childhood development.*

Esihle's description of being attentive to her son's development, noticing his needs, taking responsibility and ensuring he received the help that he needed provides a clear example of the importance of attentiveness as a first step towards enabling further care:

*I noticed him very early that he was deaf because he was less than two years old. When he was two years I noticed that he had a problem of hearing. Then I took him to get help, then he got the help that he needed.*

Rachel, a mother, described how, from the moment she saw her child, she knew that something was "not right":

When I gave birth to Brendan, I don't know man, I just saw ah—Brendan's my middle child—so I just saw, this child, there's something not right with this child, you know. I looked at his eyes—I don't know. He's not Down syndrome, neh? But when I looked in his eyes there was something that told me, Brendan, there's something wrong with this child.... I think then when the child is not fine you will spot it immediately—if you've had children. Even if you didn't have children, your mother's instinct—we were born with a mother's instinct, neh? You will know that there's something wrong with this child.

The theme of a mother's instinct is one which was evident in this excerpt. This links to the idea of mothers as caring experts, which arises in other themes as well.

When describing the time after her son's birth, Rachel also spoke about the attentiveness with which she watched her son's development. In Rachel's story, her attentiveness finally convinced the doctors to do tests on her son, after months of waiting:

Because I can see, now the development this child... This child doesn't turn his head like other children when you, you walk in the room. For one time I thought this child was blind, you know? Because the child doesn't... You know a child would move when you go there, the child would recognise you and turn the head. You go there, and he will turn his head like my other

children. He didn't, he was just lying like this and. Sometimes I would take the pen and just do this [Rachel takes a pen and waves it slowly in front of her face from side to side.] and sees if his eyes, cos I thought maybe he's blind. But he wasn't blind, you can see his eyes, if you do that [moving the pen again] and they go. But they didn't go quick, it took time to go, you know. And then I said, a simple test like that I do, you know, as a parent, I could see, no he's not, this child is not right. But I kept on saying to the doctor, "This child is not right." And then he said, "Okay, take the child for a EEG" neh? Ja.

Nozuko, another mother, also detailed how she attentively observed her son's development, so that she could tell when he had a problem, and find someone to explain the problem to her and find a solution:

*As he grows I would always observe those parts that have a problem. If only I can find someone who can explain it to me clearly that this part and this part is abnormal in this way. This part is abnormal in this way and that way, and it can be fixed when we do this and that, then the other part will be fixed later.*

*Attentiveness as essential during caregiving.*

Many of the caregivers emphasised that being attentive to children with disabilities is essential to providing quality care. Mthetheleli, a father and the only male participant in the study, described how he would advise a new parent of a child with a disability as follows:

*I would advise that parent to always monitor their child, because a child with a disability needs a lot of attention. Therefore, parents need to take good care of their child.*

Mandisa and Funeka, two mothers, spoke about how in training they learned the importance of attentiveness in order to understand one's child and his or her needs. Mandisa said,

*When we were at school we were taught that when you have a child with disability you should be more observant, in doing so you will be able to pick up some things that might help you understand your child.*

Funeka explained how the workshops helped her and other parents to learn to care for and understand their children:

*The workshops helps us on how to take care of our children with disabilities, how can you help your child, then in the process you learn to understand your child's needs.*

While talking about attending to children's needs, caregivers expressed how some children's inability to verbally communicate meant that caregivers needed to be particularly attentive in order to understand what children needs. Lulama, a carer at the edu-care centre, described it in this way:

*Sometimes a child cannot speak, so you need to think for himself. Maybe he's thirsty but he can't say, so you must be able to have eyes in order to think what he needs. Mh...*

Jacqui, a mother, spoke about her attentiveness to her daughter's needs when she feeds her. By being attentive, Jacqui was able to know when her food had settled, and know if something was not right with her daughter:

*Now like Cindy, sometimes also if she doesn't want to eat then we know something is not right with her. But I sit for hours next to Cindy. I wait until she is finished and then I tell her to pass her little wind and then I rub her like this on her back, then I know the food has settled. Now she drinks her cup of tea. But if you see that she doesn't want to eat, then you know something is wrong.*

Nomlanga, a care worker at the orphanage, explained how she would teach new carers to be attentive to children's particular needs:

*A first timer with children of disabilities I will teach that person and show her how to look after them. Mostly these children cannot speak and can't do anything for themselves, you don't even know if a child poos or wets himself, in that way I will teach that person to always check the child even when he cries, always check the child. Sometimes a child cries when he's not full in his stomach in that case I will tell that person to give a child some more food, always take care*

*of a child as your own, because in some cases a child might be hearing and can't speak, just love a child knowing that this child can't do anything for himself he depends on you.*

Nomlanga's words point to an important thread in many of the interviews about the dependence of children with disabilities on caregivers. The awareness of children's dependency served as motivation for some caregivers, and also impacted the nature of the labour of care which caregivers provided. Both of these prongs of dependency are explored in the associated sections.

### ***Prioritisation of needs.***

Another common theme relating to caregivers' attentiveness to children's needs was their prioritisation of needs. Many caregivers, particularly mothers, spoke about how they chose to attend to their children's needs first, and often instead, of attending to their own or others' needs. Nozuko, a mother, expressed her prioritisation of her son's needs as follows:

So I have to do something that's good to make him feel good. He is my first priority. So I have to put myself... I have to put him first and put my needs after.

Jacqui, another mother, and the parent support centre coordinator, spoke about how her family focussed much of their attention on prioritising the needs of her daughter Cindy. In response to a question about what it was like caring for her daughter, Jacqui replied as follows:

*Look my family was, how can I say, we became a lot closer. We had (...) more, we cared more for one another. Look my little daughter was also an adolescent, and my son. ... And then the Lord arranged it that my children grew up. Because everyone says that Cindy is the head in our house. We have to look after Cindy so that everything is right. And so they went to school, and my—and the son, I knew he would go and work after school, and some of that money he placed aside to help us. My daughter did hairdressing, and uh she has her matric in that time she completed standard 8 at nineteen along with the hair and the nails and everything, manicure and pedicure and what all is now completed. And then she also started to help us, that for Cindy we can can—how can I say it? It must be right for her. We built a hallway for her, we have that*

*area outside and even the school came to ask what they can do for me. And then for them we, that, Cindy's pavement, that pavement outside, they helped me with and the area that was built on that my baby son did for Cindy to ride with her wheelchair, and so that she can look out the sliding door. They did a lot for me, my children, it was just what we did for Cindy.*

Jacqui also described how because of her constant concern for her daughter, she chooses to stay at home with her daughter, even when someone offers to watch Cindy when Jacqui goes out. Jacqui expresses how she prefers to stay with Cindy, because that is how their relationship is, “together”:, because that is how their relationship is, “together”:

*No. (...) Like now that I, that I now that I now, went to fetch my stuff, the lady is here quickly. I can't even if I just go to town and stand in the queue. (...) Is the child not maybe having a fit? Or something can happen. I just want to stay at home, because that is me and Cindy: together. I mean going out as well, now they tell me, “Mommy, come with,” or even, “Go out to the church,” or so – No! (...). Cindy. Nah uh [shakes her head]. I would rather not, I am like that.*

Other caregivers illustrated their prioritisation of children's needs in their descriptions of their routines of caregiving, which are described in one of the sections to follow. Noticing and being attentive to children's needs, and then choosing to prioritise certain needs above others, as Jacqui and Nozuko articulated here, alludes to taking responsibility for particular needs being met. The following section explores some of the participants' experiences relating to taking responsibility and being responsible for the needs of children with disabilities.

## **2. Taking care, being responsible.**

In addition to speaking about finding out about and coming to terms with their children's disabilities, and being attentive to their children's needs, some caregivers also spoke about attitudes towards accepting responsibility for caring for their children. Some participants described stories of others who had not taken responsibility for caring for children with disabilities.

*Experiences about accepting responsibility for attending to children's needs.*

Nozuko, a mother, spoke about how as she become attentive to her child's needs, she felt she had the responsibility to attend to them:

*So you have to be there just to look, he can't roll. You have the responsibility of teaching him how to roll.*

Jacqui, a mother, chronicled a process in her life when she shifted her choices towards taking more responsibility for her daughter:

*Look I had a lot of (...) high[life] friends, and uh we liked going out a lot, now sometimes what Cindy as well – okay now not every day, but... as a person is, goes with and parties here and so and there and then I realised no man, to go and party with you on a Saturday is not right. Because by then Cindy was also grown up but I mean it's not that I made a habit of it. I just said enough is enough. Because this is my child, we must look after her. And for how many years is it now, Cindy is twenty-two. I think it was, how old was Cindy...? (...) Two or three years yes (...) when Cindy now four, five year old, when we left everything.*

Pamela, a mother, described how despite doctors trying to dissuade her from keeping her child, she insisted on retaining responsibility for caring for her child:

My child was three months and then he was getting sick in the middle of the night, then I took him to the hospital. Then after that they told me that the child will be disabled, he will be a cerebral palsy child. That's whereby the doctor called me in and told me that, "Your child is not going to make even a year. Would you like to leave the child in the hospital?" Then I told the doctor that, "No. Everything what happens to my child must happen in front of me. I'm the mother of the child. I wouldn't take my child and give away my child to the hospital because of that my child is not even going to make it for a year." Then the doctor called the social worker so that we can sit and the social worker must talk to me and the other lady who are doing the counselling whatever. Then I told them all that, "I—No, I will take my child home. If you

discharge him today I will take him home.” The doctor called me to another ward, neh? So that I can see the other disabled children. Then I said, “No, I will take my child. If my child is not going to walk, is not going to do nothing- but I’m the mother. I won’t give up my child.” Then the doctor and social worker decided, “Let us give Pamela her child.” Then I took my child, I took my child home.

Pamela’s story also highlights how she felt that as “the mother” it was her responsibility to care for the child. While the doctors in Pamela’s case seemed to be trying to convince her not to take care of her child, doctors in Nandipha’s experience emphasised her responsibility to care for her child, and that she should not let anyone else care for her child:

*So the doctor said I must make sure that I don’t leave him with anyone else to take care of him, I must not take him to crèche to be taken care of or leave him with someone to feed him. Because someone else will feed him in a hurry, or feed him the wrong food that does not agree with his condition.*

This excerpt brings attention to the idea of a mother as the primary person responsible for caring. This links to the previously mentioned idea of a mother’s instinct relating to attentiveness towards her child, and links to the theme of mothers as expert carers, both of which are explored in the section about caregivers doing the labour of care.

Nozuko, a mother, spoke about how people in her community responded to her taking responsibility for caring for a child with a disability:

*They look at me like... he's a child. They look at me like I am the child like it's like... [change to isiXhosa] They think that I deserve to be happy. It's like they think I'm wasting my time looking after this child. It feels like... when they look at me it's like as if they say you must enjoy yourself when others are enjoying themselves. Yes, I know that there's a moment you feel like you want to go out and enjoy yourself. They think that since I have this child, they feel pity...*

*My joy is to be with my child, not anyone else. I wish that people don't pity me, or worry that I deserve to go out and enjoy myself with my age group. No. I don't need that.*

***Others' refusal and acceptance of responsibility for children with disabilities.***

Recounting stories from their lives about the times when they took on responsibility for caring for children, some caregivers also spoke about others in their community who refused to accept this responsibility.

*Families acceptance/refusal of responsibility for children with disabilities.*

Pamela, a mother, described how her husband refused to accept their child, leading to their divorce. In this excerpt, Pamela also rejected her husband's notion that the child was a punishment from God, and insisted on his being a gift:

Then it's whereby, the divorce. There were problems with my marriage. Then the child's father told me that, "Here at this family, we don't have disabled children. Now where are you coming with this one?" Then I told him, "If you don't accept this child, then it's better that I must leave, with my child. I can leave the other children here, if they want to stay with you they can stay with you, then I will take my child because this is a gift from God. I can't say that I must- you can punish me because of this disabled child. No it's not like that." Then I took my child, I packed my clothes and then I go. After that, it was just a week and then my other children said that they can't stay without you mom, we are going with me, with you, because this is our brother. I started the centre, I was getting all this trainings, that is why I'm- most of the time I'm doing this home visits. I just go and have a day at parents so that they can know there is a parent who are strong and empower them.

Pamela's story also showcases how her other children—siblings of a child with a disability—actively chose to stay with their mother and their sibling, "because he is our brother." Pamela also spoke about her husband's family's response to their child, and their refusal to take responsibility for caring for him:

No ah, but my family, it was not easy for them to accept my child. Maybe when I was supposed to go to the shop they told me that I must take my child with. They can't look after the child, because my child was always doing like this [makes a gesture tensing her body]. ... As my child was fitting the time he was young. Then they thinking that the child is going to fit again but it was just that time. "No, take your child with." And I said, "No I will take my child with." Even if it was raining, they don't want to sleep with that child. Then it's whereby, the divorce.

Nozuko, a mother, spoke about how difficult it was for her that her family would not take any responsibility for caring for her child:

But, yoh! Sometimes (...) Sometimes you wish (...) that (...) your family could be better.(....) Me and my family they don't even understand (...). They don't even understand him. They don't even know how to feel. That's the, the painful thing. It's not that I want to put him there even- No. When I'm there, this they had to take him, but they don't understand him the way that they should. (unclear). I'm always there in my house, (Unclear) always home with my child. (...) It's not that, I want them to always be there always, you know. I just want them to (...) understand him (...) ... Yes, it's too difficult. (...) Even if, I manage (...) ... Sometimes when I take him there, with that, I always think like, who is going to feed him? Who is going to change the nappies so, what's the use of me putting him there, when they aren't going to do anything... Yes.

Nozuko subsequently described how her sister was the only one in her family who showed love towards her child:

The only person who always try... [is] my sister, but she's got her own family. ... She is in [another district]. ... November, December, then I always go there maybe, maybe a month. ... It feels (...) good. Cos she loves him. She only has two daughters. Now, when I'm there, she's treating him with love, cos he's a boy. So I see her loving my child.

The recognition that her sister's primary responsibility was towards her own family seemed to imply Nozuko recognising that she and her son are not her sister's primary responsibility, meaning that

although her sister cares for her and her son, this is limited by her sister's other responsibilities. In the excerpt, it is evident how much Nozuko values her sister loving her child, perhaps emphasising how uncommon this is in Nozuko's life. When asked if there was anyone else, besides centre care workers who helped Nozuko with caring for her son, she replied:

No it's just me.

Some participants did not explicitly speak about their family's rejection, but implied this when describing how they were alone in taking care of their child. In response to a question asking if anyone assisted her with caring for her daughter, Veliswa responded:

*There isn't anyone. Even when I have to go somewhere, I ask my neighbor when she's around to come and help while I'm gone.*

Although Veliswa did not seem to have support from her family, she mentioned that her neighbor is willing to assist when she goes out. Other participants also spoke about how people in their communities, besides their families, accepted or refused responsibility for caring for children.

*Community acceptance/refusal of responsibility for children with disabilities.*

Robyn, a mother, testified to how supportive and caring she felt her community was, and how willing people were to respond to her needs by assisting her:

*It is actually really good for me. I don't get uhm people that look down on me that can say, "Oh look she has a child like that!" Or, "Oh my look there she is walking without her child." But it is a very good community because everybody cares about each other. It is a very caring community and I can walk in the street and then everyone will come to say, "Hi! Look he is so cute," and so. But not once has someone said, "Oh look at how he looks!" Or, "Oh no, he's this sort of child or that sort of child!" There was not once something like that that happened. For me it is just to live in this community is, is for me ( ) I won't – I wouldn't give it a chance to go and live in another community. Just that looking down on a person, to see those negative things of a person, it won't work for me. I'll rather prefer to stay here than in another community.*

*Here it is more comfortable for me. It is very very comfortable for me here than in another community. ... It is really diff- very easy, I can ask anyone to help me. I can ask anyone. I can ask friends, I can ask neighbours, I can go to any person, if I should go in another community, then I would struggle because why would that person now want to help me? He doesn't know the situation, for me he is not going to – but here is is very very nice.*

When Mthetheleli was asked if anyone helped him with caring for his son, he responded that nobody assisted him and his wife Nobantu, with caring:

*We had no assistance at all.*

Pamela, a mother and centre coordinator of the edu-care centre, told two stories illustrating her community's lack of responsibility for two children, and how she stepped in and took responsibility:

In the morning, I was in the squatter camp. I said, "Look there are dirty water, there by the road, and somebody is sitting there." Then I go, say, "Hey!" There's a person there. It was eight in the morning. And when I go there, we go there and say, "Yoh! There is a boy, a big boy, in the dirty water." Then the people say, "Aaah!" When I called the community they must come and see [they said], "Yuh! *He stinks!*" Stink, neh? Yoh yoh yoh yoh. Then I say, "Ah ah. *The child can stink, but he's a human being. We must help him as parents now. We are mothers. Now I will take this child.*" The child was 17 years. I took him and I go to my shack, I put warm water there and my son, she washed that boy and I said, "Hey, take some of your clothes because you are wearing the same clothes as this child." Then I will look for the parents. I call there every time meetings, these council meetings, and said that I have a boy here and I asked him, "What is your name?" He told me his name but he don't know the surname. Then after that I seeking and seeking for a person of the family then one man of the other shacks, next to the railway and the station, he said, "Pamela, I hear that you looking for a person, people say that you have a child here, where is that child?" Then I say that she must come there and I called the child.

Then other people, who are afraid of that child, because when he comes he wants to hit you hit

you. When I put a bottle of the child here with me, he took that milk and he drink the milk, and he put the bottle. You know the other people are afraid of that. Then they say, “No, I know these child’s parents, he is in [another district] neh? I will check.” Then I took the child to the clinic every time, so that they can look after the child. Then it’s whereby, “Hey, Mama Pamela, you like to take all the children from this location. You must take the child home.” Then I said, “Haai! I will stay the child, until I’ve got the parents of the child.”

In another excerpt, Pamela chronicled how a child was tied to the railway line by a young parent, and how people in her community noticed and took responsibility for the child:

And that year there was a parent that, a young parent, that had this child, it was the first time that she had a child. She took this child to the railway line. Then it’s God’s way, God doesn’t want that child to die. And there were no trains coming. Although (...) it was early in the morning, the parent was thinking that the train will come, so that she can be free. Then God was just stopping the train. And there was a person who heard the child crying, he didn’t see the mother of the child. It was early early. Then she go quickly. :No! the child is crying.” Then he was just making fast with some belt whatever. Then they, the security, take the child to the police station and they called me, “Pamela, don’t you know of a parent that have a disabled child and was taking the child to the railway?” I said, “No.” Now they take the child to the social worker and then the social worker called me and ask if I can look after the child. Then I was looking for her a mother. Yes. Then she [another, unrelated mother] sign and took the child. She has a disabled child, a daughter, but she took also this one. We would do this thing where the disabled children will come to my house, I sit with them, talk, and they laugh and go home. And then that woman was doing the same as I was doing. ... Then, she took the child and then after that the mother of the child—she was very young, very young! I asked her where is her mother, because you are also young? She told me, “In the Eastern Cape. I can’t look after this child. My boyfriend said I must go, then I decide to take the child there and I didn’t know about

you that time.” Then I said, “Ok, now you can’t look after your child so you decided to take your child to the railway line. You can’t do that. You can take the child to the social worker.” ... Then we took the parent to the social worker, to the court visit. So the mother, she signed. That child passed away last year, and the child was seventeen years. ... I’m just thinking about the young ones, because they just think and they make decision, they took the wrong way.

In Pamela’s story, she also mentioned how she spoke to the child’s mother, and instructed her about acting responsibly for her child. In this illustration, it was also evident how Pamela took responsibility by caring for the child until the mother was found, and assisted by talking to the mother and connecting her with the social worker and court.

Pamela’s final comment in the quotation exhibits her concern about young parents’ decision-making. Another mother, Funeka, also spoke about young parents who do not take responsibility for their children:

*Because you find that some are taken care of by a granny in the back yard and a parent goes out drinking. Other people do not accept the disability of a child especially the young ones, we are lucky to accept it because we are older.*

***Engaging with community responses through advocacy and awareness raising.***

In response to familial or community rejection, maltreatment, or not understanding of children with disabilities, caregivers took responsibility for creating awareness and advocating for children.

For Funeka, a mother, a part of engaging with community responses to her child was comforting her child, and telling him to ignore the teases from other children and focus on his family’s love for him:

*Yes when he grows up there's that stage of 4 or 5 years. So the other kids on the street would tease him and say, hey he is limping, things like that. So you supposed to comfort him and tell him that it is not his fault that he is like this, ignore those kids don't play with them, what is important is that your mother loves you and also your family loves you. Because he can be*

*teased by the other kids on the street. Sometimes other children of the same age as him would often tease him. Even when their playing games they would say, no you are limping we don't want you here, things like that. You see. You know how our locations are.*

Giselle, a mother, described how people did not understand her son's mood changes, and that she tried to inform people about her son's condition to help them understand. Giselle also expressed her frustration when people did not respond with understanding to her son, despite her efforts to explain:

*Like (...) any types like what I understand about him now regarding him being a Down syndrome is when he is in a moody mood. He has his good days and he has his bad days. And when he has a bad day, all he wants to do the whole day is fight and, and people don't understand that. So I have asked the specialist for tranquilizers for him, but then the specialist said that he can't give me, because they are born that way, and the people in the street should just understand. They are that type of children, that moody children. They, one day they are fine then they greet the whole day, and the whole day they give kisses, give hugs and the next day when it is that fight spirit, then you should just leave, it won't help if I hit him because he will do it the whole day. Because he has his up days and... And now when he fights like that, that fighting spirit he just because people don't understand him. Then I get () I stress () I get stressed and then I get irritable and then (...) I feel like I could attack those people because they know by now what type of child I have. So they are supposed to understand my child by now, but it looks like they don't understand. And then I just take my child and go to my home.*

Like Giselle, Jacqui, another mother, recounted how she also tried to explain to people in her community that her daughter is like them, and is able to understand them too:

The beginning was very hard. They stared at Cindy—you know that that is just how children are. Then you explain to them, “Cindy is just like you. She just can't speak, she also can't walk. But dear Jesus had also for her—like you can walk and, Cindy can. And she has eight percent brain. And Cindy understands,” I tell them that as well, “Cindy understands everything.”

Boniswa, whose brother had a disability, described how she and her sister stood up for their brother when other children in the community tried to make fun of him. With time, Boniswa and her sister's efforts meant that their friends started to take responsibility for her brother, by keeping an eye out for him in the community or by helping him out:

No, the attitude towards my brother? It was not, it was bad at first. Especially with friends it was bad at first. But then they would see that me and my sister we never cared, we never cared. Heey people come here, think, "Ahahaha!" [Impersonates people laughing or making fun]. So we just, "So, so what? Is it making- why are you making fun? You never know who's—that might be you tomorrow." We gave them—we never gave them a chance ( ) that gap. So, okay fine, this one is making fun of my brother, wooh I'm going to be afraid—No! You just, we just gave them the attitude then they will say, "No man, fine!" Then at, as time goes by it was them that would bring my brother home, my friends that would bring my brother. Because maybe we would be at home, and they would say, "No, we saw him there," or no, they would just come then they will see that they already help him. They see that we never gave them that chance, that stigma that they wanted to do. Mmm. Just like, we just gave them the attitude, "So what, is it the first time you see a disabled person?" And, as time goes by...

Pamela, a mother, described how in response to taxi drivers not understanding or being accommodating to the dynamics of travelling with a child in a wheelchair, she started "doing awareness" in her community:

Then after that I was doing the awareness, on my own. I was just thinking that: So how are we going to do this, because we had a problem. I did have a problem, when I was going to the hospital with my child. Then the taxi told me that, "Mamma! You must make quick!" They don't know about the disabled children. I was having that buggy, that wheelchair. They said, "No lift that child! Take that child in! I'm in a hurry!" Then I told them, "I can't leave the wheelchair, because it is for this child. So either you can go if you are in a hurry, because I must

take the wheelchair.” So after that I decided: No, there must be some awareness, so that in my community they must know that there are disabled children. So then I was doing the awareness, I think it was 2001. It was very great because I was just going around, inviting those people in the community with a loud speaker, saying that we have this meeting and whatever. So we told them how important this disabled child is to protect. My child is your child. When you see a disabled child in the road you must protect that child, take care of that child. Maybe the most special and location they know about this disabled children. I was having every time this awarenesses in this community. ... Parents, the municipality, I make sure that the municipality, the association of the taxi’s, the clinics, the churches and the youth.

Pamela seemed to be advocating for the community to take shared responsibility for children with disabilities. In addition, Pamela spoke about the importance of protecting children with disabilities, which is something other caregivers referred to as well.

Later during her interview, Pamela talked about how she responded to the doctor’s report that her child would not live a year by taking a photo of her son every year on his birthday, and taking it to the hospital to show them he had survived. One way of conceptualising this was to see it as a habit of advocacy, or standing up for her child, and showing the doctors they were wrong. In this excerpt, Pamela also mentioned how she felt empowered to help empower other parents, and that doing so helped her to cope during a very difficult time when her child passed away:

No I am proud; at the time it was difficult for me. Every time my child is year I took a photo at the party, the birthday part, then I take it to the hospital. My child died when he was 12 years old. And at the time when my child was only three months old the doctor told me that my child will not even make it a year. Then I showed them, now my child is a year, now my child is two years. They have his pictures at the hospital. And then they said let us, in our parent meeting, let us take Pamela, because she is empowered. I was empowered by DICAG. If it was not DICAG, I wouldn’t know anything, but now I am empowered, now it is easy for me to go and empower

other parents as well. Because the time my child was sick and my child died it was not easy for me, it was very difficult. I couldn't even go out. But I was just telling myself: there is still other parents who needs me.

Another mother and the orphanage coordinator, Nobantu, spoke about how people in her community abused her son. Taking responsibility for her child, Nobantu chose to stop working so that she could care for him.

It was not nice at all. It was not nice at all. Even if he talked like that, people ask me in the community about my son. Because people abused my son, the people would abuse me and they talked the wrong things to me, they would give a drink to my son and when my son is drunk they hit my son. He was not right at all. They always kicked my son and when my son jumped over the door, because they want to go to smokkel and as soon as my son come they give a glass, and they hit my son, my son like to hit because now he is drunk they hit my son. It was very very bad. They abused my son. I'm on leave at work, I was working as char in Constantia, working as char and in Wynberg, I leaved the work, I didn't work because of my son. Because the people abused him every day, people abused him. I don't want *to bear a grudge on them*, I didn't *bear a grudge on them on*. *Why did they do that because they won't know*.

Rachel, a mother, centre coordinator and active member of DICAG, described how she engages in advocacy and awareness wherever she goes, and remarked how her husband sometimes complains a little about her continual engagement with advocacy:

My husband, when we see someone with a disability, then he calls me Innes [her second name] and he says, "Innes, *please*, don't go and talk to that person, can't we just go?" He is so worried because even because when we go out I advocate. ... We were at a wedding now recently and this woman, I just found out when she came to sit there by me, my husband was sitting, and she was like eventually talking and she had Alzheimer's and we were talking and I'm saying, "Do you have support? Do you know about DPSA [Disabled People South Africa]?" And then he

was, “We are at a wedding.” So he sometime says to me when we go out, “Please, please wherever we go, leave the people with the disabilities and the wheelchairs. Don’t bother with them on a Saturday or a Sunday.”

***Responsibility for organising attendance to children’s needs.***

Advocating and raising awareness about children was one of the ways in which parents of caregivers took responsibility for their children. Another facet of taking responsibility involved organising attendance to children’s needs. This included starting and maintaining the centres for coordinators, organising children’s access to services, making choices about who takes care of children, which I call *gatekeeping*, as well as deciding how children are cared for, such as choosing treatment options for children.

*Responsibility for care centres.*

For centre coordinators, starting the centres was an act of taking responsibility for children in their communities. It involves ongoing organisation of administration and funding to keep the centre going. For example, Pamela, who started the edu-care centre and continued as its coordinator, stated how she opened the centre to meet the need for a safe, caring place for children with disabilities:

I opened this centre for the protection and care for the children because there is no ah ah ah crèche’s in [this area] for these children.

Rachel spoke about how a social worker inspired her and other parents to start a day-care centre, so that parents could take turns sharing responsibility for each other’s children:

Then they pointed me to a social worker, Rita Johnson, I will never forget her. ... And that was the very lady that I went to that said why don’t you start a support group, and we then started a support group. And that was also the lady that suggested get the place now, because you are only there on Fridays. Why don’t you get a little place now and then you come maybe three and she suggested why don’t you, you are five parents, two parents go out and go do your hair or do something for you and you leave your two children by the three parents then there is five

children there with three parents there looking after the five children. And she assisted us in getting us a place, a little place we come thrice. We first started one day a week and then we had thrice a week. And eventually we opened a day care centre and that day care centre is still running.

Nobantu, the coordinator of the orphanage, spoke about how her experience of community abuse of children motivated her to take responsibility for children in the orphanage, in order to protect them from the abuse her son experienced:

People abused my son. That is why I keep those children because I know people are going to abuse them... I'm making those children safe. Because I don't want people, what they did to my son. They people abused my son very badly [starts crying].

By running the orphanage for children with disabilities, Nobantu took responsibility for the safety and care of the children. She later described difficulties with registration and funding, for which she took responsibility, which she encountered as the centre coordinator:

It's not easy to me because sometimes, we not registered for or had money, we registered with the NPO and we still go to register and no money provide as a government.

While Nobantu seemed to struggle to access funding from the government, Pamela, the edu-care coordinator, spoke about how the Department of Social Development has supported her centre. This points to the role of government in taking responsibility:

And the centre is registered by Social Development, and we are getting funds, we are subsidised for 60 children. They say ten disabled, because the place is small and 50 able-bodied children. We getting paid for 60 children. ... Yes, it happens, it is still happening. Because I started getting these subsidies from them in 2006. 2006, 2007 until now, they are still funding us.

Funeka, a mother, spoke about her desire for government to take more responsibility for supporting the centres of care:

If you were government I would say, you need to draw more attention to crèches that takes care of children with disabilities. Like they need to be supported, you see. They need to be supported because there are very few of those crèches here in the location, especially those that cater for children with disabilities and also children in general. I wish they can by all means be supported by the government. And give them a bigger place because that's our biggest problem here. For example because of the small space some of the parents keep their children at home. They would often say it's too full at Pamela [edu-care coordinator]. So that parents can always bring their children. You see. If they give us a bigger place more will come, because there are many children in this location, especially the small children. ... So I only wish they can get a place where there will be a centre, then we know that every child is able to go there. ... Ya you see. So if government can support us with the disabled children and provide a place, blankets, more beds, and more cots we will be happy. Because there are so many disabled children, some end up...you see. Mh...

One of the caregivers at the edu-care centre, Esihle, spoke about the need for a bigger centre that was also warmer.

*If they can build us another centre, or maybe get another site somewhere else not here. Because it's not warm enough here. If they can build for us so that we can have a right place, yes this one is also fine but if we can get a more spacious one.*

Lulama, another worker at the edu-care centre, also spoke about the centre's need for more space.

*I wish the centre can get its own place, not the way it is now. If it can get maybe a site that is spacious? This site is too small. For example even here you see eh [gestures to the small room where the interview is taking place]...You see what I mean?*

Rachel, in her capacity as a member of DICAG, described how DICAG supports centres in accessing funding and recognition. In this way, DICAG as an organisation took responsibility for care centres:

Centres that you will be visiting that has been registered, this centres that was... you're going to go to Paarl. Those was one of the centres that was in a *little hole*, you know a shack, that today is not in a shack anymore, because they got the assistance, and the, and and and and, we would refer them to funders, and and and stuff like that, they will get recognised because they under this um, um people don't want to give you money if they don't know that you're going to spend it properly, and do it properly, or there's an organisation that is guiding you to do it, you know?

One example of corroborating evidence to DICAG's support of the centres was Nobantu's statement, when describing the care centres associated with the orphanage:

I got to say, I got another centre; the first centre DICAG built in Nmzani and this is is number two.

Other instances of participants' referring to DICAG's support are presented in the section about learning to care, in which some caregivers spoke about the role of DICAG's training workshops.

Another way in which participants took responsibility for the needs of the centres was by engaging with me as the researcher during the interviews about the centres' needs, as some of the previous excerpts demonstrated. Pamela, the edu-care coordinator, told me about the centre's need for a piece of land, and the necessity of letters of support for the application, one of which she did not have yet:

Yes, the building issue, neh. It's a piece of land. Because they told me that I must get a letter from another organization to support my application. Then I'm just sitting with two letters from DPSA and DICAG. But they say there must be three. But they just promise, so I don't know if they are going to do that.

After the interview, Pamela asked me if I, as a Stellenbosch University affiliate, could write the third letter of support for the centre's application. In this way, Pameal exhibited resourcefulness in her acts of responsibility for the centre.

*Responsibility for organising children's access to infrastructure.*

In a similar way to how centre coordinators took responsibility by accessing funding for the centres, some mothers took responsibility by accessing government disability grants to provide for their children. The effort required by parents to access the grant provided by the government for their children demonstrates how the need for both agents of care to take responsibility in order for the needs of children to be met.

Pamela recounted how when her child was young, it was difficult to access the grant, although government provided some support in the form of food packages.

Because I get some money, that time it was difficult for a disabled child to get a grant. They say that a child must have three years at that time. ... But now it's easy now, if a child is born disabled they get a grant. That time with my child, 1994, the child must be three years. But what I like was the social service was giving some food package for those parents, use it for our children.

Nandipha, a mother, explained how she felt that others in her community did not understand that she uses the grant money to take care of her child's needs :

*Sometime you will hear them when they chat saying thing like, "This one has lots of money because she gets a child grant, and that's a lot of money." But you as parent on the other hand, you know that this money does not meet your child's needs, because you use that grant for everything that he needs, including paying for life insurance.*

As Nandipha's words suggest, some participants felt that the grant money was not enough to meet their child's needs. Financial difficulties experienced by caregivers is further explored in the section about challenges during the labour of care.

Funeka, a mother, spoke about the inaccessibility of libraries for children with disabilities. This illustrates her taking responsibility for children's access to infrastructure, and illustrates her view that

the government has not taken sufficient responsibility for providing accessible libraries for children with disabilities:

*But the government does not care about the issue of people with disabilities. Even here there's only one library and that library is for abled children who can do everything, you see. Is there anyone there who can... assist that much for children with disabilities.*

Rachel, a mother, spoke about the importance of children with disabilities being able to access education. Rachel advocated for the importance of parental empowerment so that parents could take responsibility for sending their children to school.

There is children in rural areas they get education, those that are educated that can be educated, they need the education so that we can turn the tide around. When cannot, not not leave people uneducated because 15 years from now another student will come and sit around the table, looking at the same problem because we are not doing what we are supposed to do. So we need to empower parents and we need to empower parents so that the parent can go, eh, my child got the right to education, I must send my child to be educated. Then I'm saying again, children with physical disabilities that can be educated, if proven, that you know, you've read books and stuff, about a lot of prominent people with disabilities that do excellent work. So we also want to see that, our children with physical disabilities must go into mainstream you know. Some with Down syndrome some with autism children, autism they can also be mainstream. They must just get the necessary support.

Another way that caregivers took responsibility for children was by delegating caring responsibilities to others. This included bringing children to hospital to be cared for by health-professionals, sending children to centres to be cared for by others, or asking trusted individuals to provide relief care for mothers. The next two sections outline how care workers at the centres and mothers took responsibility for delegating and gatekeeping who provided care for children.

*Responsibility for gatekeeping at the centres.*

The orphanage coordinator, Nobantu, spoke about responsibilities for organising care for children at the centre when they became sick:

But if they are very sick, maybe sick and don't want to stop, then we call the ambulance, the ambulance comes to take the child go to the hospital, with somebody, with somebody. This is a team, it's hurting me because but if I must go to hospital, I sit there. Somebody must sit there in the night. Somebody must sit there in the day; this is a team. I said last week that there is a time that I'm going to give up because I don't have somebody to sit in the night or to sit in the day. Because the staff is short in the organization. But somebody must sit, and the mother does not want to go sit there in the hospital.

As the orphanage coordinator, Nobantu also spoke about difficulties with having sufficient staff at the orphanage to care for the children. She mentioned how she asked student volunteers to assist them at the centre, in order to meet the need for caregivers:

Six disabled children. There's not enough caregivers; the students help me. ... Got the students [volunteers from an international organisation] who help me. That's why we always contact them to be here. ... It's getting difficulty, we haven't got enough staff.

For centre workers, being responsible for who took care of the children included hiring new carers at the centres. At the orphanage, the caregivers took care with who they employed. Mthetheleli, a father and husband of the coordinator, said,

*Yes, before we start accepting that person, we take him to the rooms and show them the children and then ask if he will manage to work here. Unfortunately, some people are honest enough to say they won't be able to do so. Some say they'll manage and try to learn as time goes by.*

At the centres, being responsible for the children also involved training the new caregivers to care properly for children with disabilities. Boniswa, a sibling and worker at the orphanage, expressed her concern about how new caregivers treat children:

With a new carer, no, eeh- for- it's a bit difficult because that person doesn't know anything. Then you have to s- watch them step by step, especially with the disabled ones, how they care, how their face react, because that's another thing. The, the disabled children: They can't talk but they can see their face. If your face is wrong they will not open up. That's what I tell them, "If your- if you change your face when you change them and you make like this [makes a disgusted face] then they will say, 'Wooh!' Then they will have an attitude towards you. But then if your face is always smiling, then they will open up to you."

*Responsibility for gatekeeping as a mother:*

For mothers, gatekeeping included occasionally asking trusted individuals to provide relief care for their children, and sending their children to a centre or school when possible. For some mothers, being responsible for children's needs also included thinking about who would take over responsibility for their children should they die.

Giselle, a mother, spoke about how her son sleeps in the bed between her and her husband, so that he does not fall off and hurt himself. Giselle described how despite her other son's offer to supervise her son with a disability at night, Giselle refused because she is concerned about his knowledge of caring for her son. This excerpt illustrates Giselle's role as a gatekeeper, and links to how she and her husband prioritise their son's needs:

*No, it is only the sleep because he is one – he is not allowed to sleep alone. He must sleep with us and he must sleep in the middle because he is one that vomits in the night or he lies diagonal [across the bed] because sometimes I wake up and then, then his head is off [the bed] or I feel him or I feel he is lying uncovered. He is not allowed to lie alone because we are scared that he might fall off.... No, there is not a problem with me and my husband because he sleeps with us. But sometimes my husband moan's that he is tired and then he comes and lies ugly and then I tell him, my husband you know this is our child and he can't lie alone. We have to keep an eye on him. My one son said, my one son wants him to come and lie with him, and I told him no, I*

*won't be able to sleep without him because I know how he sleeps and you don't know how he sleeps yet, because he hasn't slept with you yet. So rather leave him with me on the bed. I told my husband you must move over a bunch. But he is going to stay there, until I feel (...) he can go in his own bed.*

Nozuko, a mother, spoke about how she did not feel she could trust anybody else with caring for her child.

Mh, I am not doing anything because ... you know, my baby needs all the care that he can get. So I don't trust anyone... maybe she or he can't take care... like the way I can because he is on treatment, so I have to just take care of him. Yes, so not doing anything, just sitting and take care of him so that he can like [changes to isiXhosa] *get all the help he can get*.

Later in the interview, Nozuko spoke about how negative experiences with people in her family motivated her to choose carefully who she allowed to care for her son:

That's why, I don't know how to put it, I don't have to chase people away from my child. But I have to think... I have to think of him.

Despite articulating that she did not trust anyone else to care for her son, Nozuko later talked about how when she really needed to do something, there was a woman who ran a crèche whom she trusted to care for her son:

No, most of the times it's me, but sometimes I do take him to the crèche. There is a crèche in Nana Street. Mh, so sometimes if I have got something that I am going to do, that's going to take all the time I have, I have to take him there, because of that lady she's got the crèche, for disabled childs, if they are not the same... What would... I do trust her because of she's got a child who is the same, so she knows how to take care.

Some participants also expressed concerns about who would take responsibility for caring for their child after they passed away. Thobeka, a mother, expressed it in this way,

*One thing I can say is that, I wish one day our children can get their own centre, because one day we will pass away and they will need their own place because no one else can look after our children. Because you can't just (unclear) your child... you are the only one.*

Giselle, another mother, described how fearful she felt, because she was the only one taking responsibility for looking after her son, and she did not know what would happen if she passed away,

*Yes, I have big fears, I am scared if I pass away and he what will my child, that and he ( ) I fight his battles for him. And I am just scared that he can't [fight] his own battles and that people will walk over him and then I'm not here to protect him. That is my biggest fear.*

Rachel talked about how she has taught her family that they are all responsible for taking care of Brendan, her son. For Rachel, she knows that her family will take care of her son if she passes away,

*Sometimes all of us, and the other thing that I want to say to you the family, the whole family plays a role, in raising this child. I had my whole family, I'm like this, I will say to myself, this is not just my child, this is your child also' I will halfway force them, you have to and if I have to go somewhere I would tell them you all have to look after Brendan. It's family, it's our child, it's your brother, we family has to stand together. I'll do that until it becomes I have brainwashed them, brainwash in a good way. They now know this is their brother and they have to look after their brother. If I die, I said to them, they will each one have to take Brendan for six months you know.*

*Responsibility for making choices about care practices*

For some participants, one of the activities associated with taking responsibility was making choices about treatment options for their children. Jacqui, a mother, spoke about how she chose to forgo further efforts to try to make certain aspects of her daughter more “normal,” because it would have meant more pain for her daughter.

*Yes if it has to come then- how can I say – for therapy and so now, but we were there with them and uh but then the (...) uh the muscles were too stiff then they had to, otherwise they would've*

*had to break her hand again. Then I said no. Rather leave it. Because look, she is what she is now- why do we have to go again doing more stuff to her. She is fine. I say that myself, but – we always rub it but now the muscles are already ( ) too stiff already, but the hand does open. And then we rub it just like this. Even now one day we picked her up so that she can stand. Then she couldn't so she cried then I saw: no man. She has gets sore in here. And then I just lay her down again.*

Nobantu, a mother, spoke about difficulties with making decisions about her son's responsibility for himself. When her son grew up, he wanted to live outside the house, but she and her husband wanted him to stay inside with them so that they could monitor him if he had an epileptic fit. Nobantu and her husband chose to give their son the freedom to live outside the house, and one day he had a fit when nobody was there, and passed away:

My son, my son, my loving son, there was no-one here. My son was disabled and in mental. I grow my son. My son, me and my husband loved my son. My son didn't go to school because of sick, (unclear) but one day my son was fits, unfortunately he was alone in a room and he fall on the bed (unclear) and if somebody will called us. ... My son was grown, twenty- twenty seven, but one day my son was fit unfortunately, was alone in a room and he fall on the bed like that. And he didn't tell us that he was fall over and he was, and somebody was call us. My son was 27 turning 28, he didn't stay with us, he said, "I don' t want to." He say, "I'm big enough" but everyday he come to us. But we was waiting for him at quarter to eight in that night other lady called us my son is sick. They didn't tell us my son has died. We go there and we see my son has died. Because he was got fits, it's not a problem...

Rachel, a mother, argued how lack of knowledge about caring for children with disabilities made caring more difficult, and impacted how parents made choices about caring for their children.

Information should be given to parents at hospitals at birth so that they understand- even if it's not a child with a disability. But you must understand the child as a whole, because you had a

youngster giving birth to a child, that even that doesn't know how to work with a child, because nobody taught us how to, how to parent. You know, you didn't get parental training. Nobody got parental training, but people just did what the mother did or what the granny did or what this one did. But it's difficult with the child with a disability.

Hence people, how can I say it, they sort of hid their children because they didn't know what to do with their children, you know? I used to put a lock on my door, a lock on my gate. Because I was afraid of, in the community I stay there is a road outside, there is taxi's up and down so I'm scared the child will just run up to it. But I mean, people do sit things for certain reasons.

In this excerpt, Rachel also described making a choice to keep her child locked behind a gate in the yard to protect her child from running out into the road, and referenced other parents who would hide their children. Later in her interview, Rachel described another situation in which she was struggling to decide about the best choice of care for her son, in which she tried to weigh up different consequences about how to respond to her son's sexual development.

Now that you speak you know what is so important when you care for these children, they go through certain milestones and when they get to 18, 19 they also have sexual feelings. They might have disabilities but they also have feelings. So it's very important for us to get the training and understanding of the sexual part of the children also. And Brendan had this, I don't know how he discovered this, but thing that is shining, tricot—it's a shining, almost like a satin fabric, I don't know how he got to that, but he likes the satin fabric and he would put it then there by his knees. It's almost like he gets a good idea I think, he discovered that his penis erects, you know? So he discovered that.

That was a problem for me that I had to deal with, and I never thought of that, but eventually I would also have to say that okay this child you almost like this child doesn't have feelings. This child will never take a wife, this child doesn't need that but the child has to go through that and I think that maybe for parents, we need to get advice from the doctors or sex

therapist or whatever what do we do in that instances when that children reach that peak, because I am still struggling with that you know. He is 30 years old and I just think I needed to train him you know, even if he was sitting and he doesn't have a ..., he will just take his hands like that and make like this. Now I need to hit him and say, "Don't do that, don't do that!" And I am still struggling with that today you know. Now I will just tell him, "Go to your room!" ... So now I keep on saying, go to your room and now he does this thing in his room and then he does it in his little room. It's not a nice thing for me, I am worried about what I must do. Do I put him on- Now I'm the type of person I will look and see, okay I spoken to a person and I said to this lady, she is up in the road, this child is forty already and one day I how do you cope with that? She said that she said, "No, I just put him on the tablet before he got like that." But you know how that child looks, that child is as thin as Brendan but that child has like, he's gone so fat you know. Now I think if I put Brendan on that thing, if he gets fat like that how am I going to handle him? ... So you're monitoring, and we're working with the doctors you know because sometimes, these tablets make... I feel that tablets, the children get addicted, his system gets used to it, afterwards it doesn't help him anymore. It just does something else to the children like that tablet, that lady is giving her child. Her child is so obese, you know? But but but she feels that—now I just don't want Brendan to get obese, I'm sorry. Then I would rather sit with this thing where, you know, I control the sexual, what you call it, sexual urges, it comes. I try and control it, he goes to his room.

### **3. Caregiving, being competent.**

After noticing children's needs and taking responsibility for attending to them—whether as a mother, father, sibling or care worker, participants engaged in the labour of caring. In their stories about doing the work of caring for children, participants spoke about their motivations for caring, the process of learning to care and teaching others to care, aspects of care work which they enjoyed and that which

they found challenging, practical components of care work, time commitments and life-style implications of care work, and necessary virtues for providing good care.

***Motivations for doing care work.***

Participants expressed a variety of motivations for engaging in care work for children with disabilities. For two of the participants said their motivation for caring at the centres was because they needed jobs. Nomlanga, who worked at the orphanage, said,

*I was looking for a job and I found out that the only job with vacancies was this of children with disabilities so, I took it.*

Thembi, a sibling, daughter of the edu-care coordinator, and careworker the edu-care centre, said,

I don't like actually um working at a centre. It's not my thing. But I'm doing it because I have to, because there's not job mos it's like, it's like... I don't know what I don't, what I don't like, but I just, I don't know. It's not something that I want to, like, want to work, with, uh, d, uh. At any actually school or any creche or, ja. But actually I love working with children, very much... I was actually (...) I wanted to work like (...) ah at the at the like a being a nurse, neh, and working with babies, and stuff like that. But I'm very, I'm fine here, there's nothing wrong.

Nobuhle, who was a new carer at the orphanage, said that she was motivated by a desire to help the centre coordinator:

*I used to come and visit mama [the centre coordinator], she used to bake and did everything, so I used to come and help her because she had no one to help her. Yes, there was no one then, so I decided that I can't just leave her like that, so I came from time to time.*

Zimkhitha, who worked at the edu-care centre said that her motivation was her love for the children:

*The reason why I work here, yho! It's because I love children very much.*

Nomlanga, a carer at the edu-care centre, spoke about caring for children as being her duty, expressed feeling further motivated by children's dependency on others to meet their needs, and by a belief that

God would reward her for taking care of the children. Nomlanga also expressed how sometimes one might not feel like caring for the child, if one was not being mindful that the child was God's creation:

*I love children with disabilities. The reason for me to love them it's because they are God's creation, they can't do anything for themselves and so it's my duty then to look after them and do everything that needs to be done for them. ... Sometimes a person might feel like I don't love this child, why is this child like this and I can't live with a child like this, forgetting that this is God's creation. ... So as a caregiver I know I'm not doing this for anybody else but for a child I'm looking after. I know that one day my reward will be from God; saying thank you for taking good care of my child.*

Another carer who worked at the orphanage, Gloria, said that seeing the caring of the hospital staff when her daughter was in hospital inspired her to become a caregiver at the orphanage,

I was in hospital with my child. She was there for five weeks . So I saw there many many children, disabled children, or children with many many problems. I saw the nurses in there, in [name of hospital]. I saw the nurses their love, their patience with them. So, that's what inspired me to look after children, it gives me power so that I can help any children because I saw many different children there with different diseases and I saw children here where I am working with different diseases and they are disabled... So, that makes me, to be very very, what, it inspired me to work with them

Another of the motivations for participants' caring at a centre was because they had previously had a child with a disability who had passed away. Nobantu, a mother and centre-coordinator of the orphanage, explained her motivation as follows,

And, and why, why you do that? It's your passion or what? We push you, you know there are passions of what you are supposed to do, I'm the owner of the business, I'm the dreamer, I dream of this centre, I dream of other centres but. But, because of my child was disabled, my son, disabled the time over ten years. I found DICAG, my son was still alive, and I joined

DICAG. DICAG trained us, my son was passed away, but DICAG always, no matter that your son has passed away, you are still a parent. You still enrolled, because we are a parent. So I can't give up because I always think about my son. You know anything I do, with what passion, is because of my son. I know it's very heavy but I love it, the job.... I love it because I think about my son.

Nobantu restated her motivations as follows,

My work? I love my work because if I do my work, I see my son. Two, I love the children. Three, you can't do nothing at work if you don't like it. You can't do nothing with special, if you don't like it, no matter that you need the money, you can't do that. It's not a money thing, it is a love. So I do that for love. Every day, me and my husband we wake up because we do that.

Nobantu's utterance highlights different motivations for caring, such as her son, but also motivations of loving the children, enjoying the work, and the idea that one should not just do care work for money.

Bonsiwa, who also worked at the orphanage,

Mm, much a- much happy although it doesn't—I don't have much money, but I'm happy. I believe now neh not everything's all about money. Money is there, but you can have money, but you're not happy, and not comfortable to be working where you are. But I'm comfortable, yes, I don't have a lot of money but (...) there are people that who have my qualifications that have nice houses and stuff. But they are not happy and I believe (unclear) I'm here, and I'm happy with what I'm doing.

***Experience of care work.***

*Enjoyment of caring.*

As some of the motivation-related excerpts illustrated, many of the caregivers expressed feeling happy or enjoying caring for children. Boniswa said, "I'm here, and I'm happy with what I'm doing".

Nobantu expressed how she "loves [her] work". Nozibele, Lulama, and Zimkhitha, caregivers who

worked at the edu-care centre, also spoke about enjoying their work. Nozibele said, “*At work I love taking care of small children because I love them. So I love my work.*” Lulama, a teacher, expressed it in this way, “*Yes, I love teaching children, I very much enjoy my work. Yes, I enjoy it very much.*” Zimkhitha, the cook at the edu-care centre, said, “*I enjoy cooking for the children... I enjoy it because I love kids very much, I really love them and I enjoy cooking for them.*” Veliswa expressed her enjoyment of playing with the children in the centre where she worked:

*I play a lot with children. It's very nice to be around them unlike being around grown up people. Children love to play. And even when its feeding time I always play to get them eat, because if you don't they won't eat. So I enjoy it.*

Although Thembi mentioned that working at the edu-care centre was not her ideal job in the excerpt under motivation, later in the interview she said she did enjoy her work, and explained that she particularly enjoyed working with the children with disabilities—more so than with the other children at the centre:

Actually I'm enjoying it neh?... I a- I enjoy- I enjoy it more to work with people with children with disabilities than the others they are very hectic. Ja you see so I actually like them very much because they can actually listen very very well.

Esihle, who also worked at the edu-care, also spoke about how obedient the children with disabilities were, and that was part of why she enjoyed working with them:

*They do whatever you ask them to do. They always stick to what you tell them, that is why I love them. If you go and take care of something else he will stay the way you left him. But that side, you would say 'sit here' and then one look away he is gone, and when you go back to attend to the other one, away he went also. This side you say 'sit here', she sits here.*

Mandisa, a mother who ran a centre for children with disabilities in the past, expressed her enjoyment of caring as follows:

*Because I had a child of my own who was disabled, I loved taking care of the children with disabilities. ... I really enjoyed looking after children here. I used to watch them looking after each other. I remember there was this child who used to cry a lot and another one would come and pick him up and say, "Please don't cry." I would sometimes be sad to see them doing that, because you would hear this child saying, "Please don't cry, please don't cry!"*

Nozuko, another mother, spoke about her enjoyment of spending time with her son:

*I got used to him. So now I enjoy being with him, there is nothing I enjoy the most than being with him.*

Like Nozuko, Giselle, also a mother, spoke about enjoying spending time with her son. She explained she was satisfied with her job as a char two days a week, because it meant being able to spend time at home with him:

*But the jobs are (...) I am fine with that. I- I don't want a fulltime job. The two days or if someone asks me, three days char or two days is fine for me. I enjoy the days off at home with him.*

Part of what some caregivers at the centres enjoyed was caring alongside their co-workers. Zimkhitha, Lulama, and Nozibele, all three of whom worked at the edu-care centre, expressed this view. Zimkhitha described how,

*I enjoy working with them because we all get along together. When I see something wrong with the child, I am able to tell the other caregiver that the child needs some assistance. We all enjoy working together.*

Lulama responded to a question about working with other carers in the following way:

*It's fine we assist each other, so it's enjoyable in that way.*

Nozibele said,

*We enjoy working together, we have nothing against each other. No gossips about someone or for an example (unclear) laugh at someone behind her back. Even when I'm not feeling well they go and check on me.*

Nobuhle, one of the new carers at the orphanage, expressed her enjoyment of working with her colleagues:

*Yhu I enjoy it very much. ... What can I say... we chat, make jokes, and the work continues [laughing].*

Mthetheleli, a father and husband of the coordinator of the orphanage, spoke about how although he and other carers used to experience challenges, they now enjoy caring for the children:

*No, we no longer experience any challenges, what we experience now is joy and we enjoying looking after the children with disabilities.*

*Caring as a challenge*

Robyn, a mother, spoke about how she experiences having a son with a disability as a challenge, and that she enjoys having this challenge in life.

*It actually feels really good to me. It feels very good to me because ( ) my my girl child is normal and now my little boy is not normal. It is almost like it is a challenge for me, as a challenge for me. It is a challenge for me, yes. And I feel I take it day by day. Small step by small step, I take it on. So one just- so much – to say that he is not normal and that one is normal, it gives me ( ) more hope in life, it gives me more hope in life.*

Quite a few caregivers spoke about feeling like caring for a child with a disability was difficult.

Nobuhle who had only recently started working at the orphanage described how it was not easy at first:

*When you start working with children it's not easy, especially caring for the disabled children. But when you get used to them you give them that love and be able to clean them and bring them closer.*

Giselle, a mother, also spoke about her experiences as difficult:

*Sometimes it is a little bit hard. How do I explain (...) I can only (...): It goes, it is difficult, it really is difficult to take care of a disabled child.*

Jacqui started crying as she spoke about feeling like it was sometimes difficult to care for her daughter, although she also experienced it as a pleasure in some ways:

*Sometimes (...) [starts crying a little] sometimes it's a little hard for me ... but it is a pleasure for me to work with Cindy, but sometimes it's also... – but the Lord gives one the strength and courage. Yes, I've been through a lot of things.*

### ***Specific challenges of care work.***

As well as speaking about caregiving as a challenging experience, some participants also spoke about specific difficulties they encountered while doing the work of care. Four areas which stood out as challenging were caring for children when they became sick; travelling with children; attending to children's needs without sufficient finances; and caring for children while dealing with caregivers' own aging.

#### *When children get sick*

Quite a few caregivers detailed difficulties when children became ill, including experiencing epileptic seizures. Giselle, a mother, talked about how difficult it was when her son became sick and she was unable to help him:

*When it is the most difficult for me is when, when he gets sick and I'm not able to help him. And I know it means taking him to the hospital and to the doctor, that is the most difficult time of my life and then I begin to struggle.*

Robyn, another mother, spoke about her struggle when her son gets seizures. Part of her struggle seems to be a fear of her son going into a coma, and her trying to act quickly enough to prevent this:

*It is really hard because sometimes it's (...) he gets the fits and then I might not be at home, then it's a little, rather difficult. I must go to the hospital. There is no way that I can stop it. And it is really difficult. And sometimes he gets it so high [extreme] that he might go into a coma.*

*That he might, yes... But sometimes—but for me it is—I act too quickly, before he can go into a coma, I act too quickly to get to a hospital. (...) But it has never happened that things go so far.*

One of the orphanage carers, Gloria, also described how challenging it was when children had epileptic seizures. Gloria expressed her difficulty about not knowing how to respond to a child having a seizure, emphasising that the last time they received training at the centre for this was in 2005:

The epilepsy children, what to do if the child gets that, the attack, what to do. So it was, I think 2005, so we need more, because when you work with children there is a lot of challenges, we need to be aware of the challenges, we need enough information to save so when we are busy waiting for the mom, is at work, so the boss doesn't allow what to do with the child, what to do with the child now, the child is having a fit now! So what must I do.

Jacqui, a mother, explained how because her daughter sometimes vomits when she is ill, she always sleeps next to her daughter, so that she can be alert if her daughter vomits.

*Now and uh if she's got a cold then it is a little bit difficult because she vomits too. Now this what I now, me and Cindy, we lie in the big bed. It's actually her bed that we had especially made for her but now me and her both lie on the big one so that I can lie next to her so if she vomits then she just pushes me.*

*When I travel with my child with a disability*

Another challenge for many caregivers was travelling with their child. Rachel, a mother, summarised her view of the importance of accessible transport for children with disabilities, highlighting how often children's access to other services, such as health services, is dependent on accessible transport:

The last thing that I want to say is the department, because the children with disabilities will need transport. Transport is inaccessible, they need health services. How do they get to their health services if it is not accessible?

When Rachel spoke about her difficulties with transporting her son, the issue she highlighted was not structural inaccessibility of transport, but the social discomfort she experienced:

You know, because I sometimes didn't want to go with Brendan in the taxi because he was funny and ( ) people didn't understand him. And he would come up to you and say like, "Uhahuhuwa" in your face, [makes a mixture of nodding and shaking head movement, coming closer to the interviewer] you know, and you wouldn't like that, you know. So it's for me it was embarrassing. But it's not embarrassing for him, he will go close up to you, but because you don't know him, you don't, you wouldn't like that, you know: This child just comes, ah, close up to you. People are more assertive now but then it wasn't such a good thing. People didn't understand, they see people as uncomfortable.

Veliswa, a mother, spoke about how not having her own transport meant that in emergencies when her daughter was having a fit, she was dependent on the ambulance to transport her, which would sometimes take a long time to arrive. She also mentioned how her husband had left her alone to cope with these challenges of caring for their daughter:

*So he left me alone in a situation like that, rushing in and out of the clinics to get help for my daughter. I don't have my own transport so I would sometimes call an ambulance and it will take time to arrive. And when it does they will ask me how long the epilepsy took, at times I wouldn't remember at all. I still can't seem to get used to my daughter's situation.*

Another mother, Thobeka, also spoke about difficulties with transporting her son to and from hospitals and clinics. Thobeka described how she had to take many modes of transport with her son, and how in later years she had to hire a car, which was a financial burden:

When he was growing up it was difficult. ... Yes he was born there, after that every time I was getting treatment in [the hospital]. But now that time it was because I must take train to [the hospital]. You will see that the train I take is full. I must go to [the hospital] with the train, when I came to [the hospital] I must take taxi to [the hospital], but after that, I must get the

ambulance. Every month I was in [the hospital], til the child was 3 years old. ...But after time I came with him at home. When I come home I must take him in physio here in [this] hospital, but now that was heavy because every week I must hire a car. Then every week I must pay that money every week.

Later in her interview, Thobeka added how travelling with her son is difficult when it's raining because the verandas of the houses in her area are not wheel-chair friendly, and there is the added pressure of not being able to miss his clinic dates:

*The problem that I have about him is when we take him to the clinic you see, and maybe it's raining. Now I don't know how am I going to take out the wheelchair because our house's verandas are not wheelchair -friendly. Even if it's raining you know I must maybe I must push that wheelchair even if it's raining (unclear) because you can't miss his date.*

*When there is not enough money for caring*

As alluded to in some excerpts already, caregivers also spoke about difficulties with providing for children's needs as a result of insufficient finances.

Mandisa, a mother and crèche coordinator, spoke about her difficulties providing for the children in her crèche when she did not have enough money. Mandisa argued that the government was not fulfilling its responsibility to provide money to her crèche, but said she does not worry because God sometimes sends someone to bring some food for the children.

*I really love children my child, it's just that sometimes I struggle a lot in my crèche. There are times where there will be no food for children and it's all because Social Service doesn't give us money and I don't know the reason for that. We were sometimes told to build decent homes but where's the money to buy the material for that. Anyway, I never worry about that, because God would just send someone out of nowhere bringing food for the children.*

Nandipha, a mother, talked about how she uses the grant from the government to meet her son's needs, but that it is not enough. She also adds how she cannot work to get extra money, because she has to take care of her son, since other people might feed him incorrectly causing him to choke:

*His grant money is not enough because he uses nappies, I spend it on nappies, his food, I buy almost everything with the grant, including electricity. I also bought him tekkies with his grant, and I have to use the same money to buy his clothes because there is no other allowance that I receive. That part is really hard. I can't go to work because I have to take care of him myself I can't take her to crèche because of his condition. His throat is small so when someone else feeds him he chokes easily.*

Another mother, Robyn, spoke about difficulties affording nappies for her child, and how she struggled when she ran out of nappies for her son:

*Yes but sometimes, some days are difficult, and other days thing go well. Like sometimes, closer to the end of the month, then there is- I don't have any kimbies [nappies] for him. I struggle a little with that,*

Giselle also spoke about needing to provide nappies for her son, and testified that the grant helped somewhat to afford them and other things she needed for her child:

*It was really difficult. But after a while it wasn't – it wasn't as difficult anymore. With the allowance I receive, it helps me out a little bit more, especially with his Kimbies [nappies] and other stuff.*

Boniswa, who worked at the orphanage and had family of her own, spoke about how not being paid for her work at the orphanage meant that providing financially for her family at the end of the month was stressful. Boniswa also described how she works an extra job lifting children home from school in the afternoons to survive. In addition, Boniswa described the process of re-registration of the centre, which would eventually enable the centre to get funding and her to get a salary:

Because (....) if I was not passionate about the job, the children, it would be heavy and stressful, and end- now it's the end of the months: stress, stress, stress and bills and stuff, I'm stressing. ... No, fine, fine! We just—as long as everybody is fine, surviving, the girls [her daughters] are there. I'm not getting salary you know! A Cent, cent, cent, cent here. ... I'm picking school children from the location, take them to the schools, that's how I'm surviving... nothing else. ... We are busy with the re-registration. ... Then after that they will register us, and after that they will- we going to apply for funding. Then I will get some salary, a salary, and maybe that will be next year March.

*When I get old*

Another of the challenges articulated by caregivers was struggling to care for their children as they became old, which included physical difficulties with doing the work of caring, as well as concerns about who would take responsibility from the primary caregivers when they could no longer do the work. This subtheme also links to caregivers' concerns about who would care for their children when they passed away.

Nomlanga, one of the orphanage workers, remarked how caring is becoming physically challenging for her:

*One of the difficulties is that because of my age and arthritis, some of the chores is quite heavy for me but anything than that no shame I really enjoy doing my work.*

Rachel, a mother, detailed her concerns about caring for her son as she gets older as follows:

Because the thing is this: I don't know what to do with that sexually, you know. So I put him in the bath but if I'm going to put him on the tablet [to deal with his sexual urges], this is what's going on in my head as a mother. If he gets fatter, I'm getting old—59 neh,, you know I'm going to be 60? Yes I look after myself very well, I don't drink, I don't smoke and stuff like that and I feel I carry my age well. But my point is this; I must also be realistic. How am I going to cope with this child when I'm 70 and this child outlives me, you know? Because he is still as

strong as a horse, and now he is 30, and when I'm going to be 65, he is going to be 35 you know, 36. So my point is this, how am I going to put him in the bath? We don't have services with children or workers who comes around. That is a need in our community you know so I feel we need to look at how do we assist these children if their parents get old, you know there should be some system, and there is no places to put these children. Okay, you can maybe say they should go to a home, you know but there is no places, these children go on waiting lists, you know and there is no places for them to go to so what do we do? You know that's a challenge that you need to look at, what do you as a parent when the parents are now getting old, what do we do with these children, you know. We fought for them not to be excluded from the family, we used to fight that our children are not put into a home and are separated from the family. So they got the families support and they struggle through the years but now we are getting old, how do we cope with that? So I'm fearful to put Brendan on that tablet because in my mind I'm thinking that he is going to get fat, I must lift him up, I must take him out of the bath, you know?

Alongside difficulties with physically caring for her son, Rachel's story links to other themes in the findings, such as difficulties with making choices about care options, and challenges with who takes responsibility for people with disabilities.

Thobeka, another mother, also spoke about difficulties doing the labour of care for her son since she was getting old and had diabetes, meaning she had to go to the hospital periodically:

But now it is difficult because now that I'm now old *it is difficult* now, heavy now to pick him up washing for him, and now I'm diabetes (unclear) that maybe I must be in hospital for three weeks. Every month I being sick and there was nobody to look for her. Because I have children but my children are working and now it was difficult that I must leave him at home.

Nobantu, a mother and coordinator of the orphanage, also spoke about her concerns due to getting old.

Not only did she find care work itself difficult, but she was concerned about who would carry on

helping at the centre. She mentioned that although her daughter Boniswa was helping at the centre, she had her own family and could choose to go elsewhere:

But the problem hurting me is my age. Include disability. That's why my children help me. But my question is that how long is my children going to help me? Because my children, they got their own degrees. They want to work, they got their own children and own houses. And another thing that is a problem is she [Bonsiwa], she is a qualified lady, she is qualified but she has children, three children, she want her own needs. She's working here, she was working the time she's got money, if we got the funds she can go anywhere.

The excerpts from Nobantu, Thobeka, and Rachel all illustrate concerns about who will assist with caring for children with disabilities when the current caregivers are too old to continue. This links to the aforementioned concern of caregivers about who takes responsibility for children after caregivers pass away.

### ***Coping with difficulties of care work.***

Caregivers talked about different methods of coping with difficulties they experienced. These included referring to God as a source of strength, as Jacqui did. Caregivers also spoke about “getting used to it” as a process through which they adjusted. Lastly, caregivers talked about people who supported them and helped them to cope.

#### *Prayer and strength from God*

Like Jacqui, other caregivers also referred to receiving strength from God. Rachel, a mother, stated, “I’m also a very church going person. I pray a lot and I believe in God, I trust God, so you know. I used to get my strength from God and minister.” Nomlanga, who worked at the orphanage, also spoke about how both God and enabled her to do caring work. “*But God gave me strength to do my job and I’m doing it.*” Thobeka, a mother, recounted how she prayed to God to help her cope, “*Because I would tell myself that I would pray... I would pray and say, God you are the only one who knows you gave me this child, now can you please help me so that this matter does not stress me.*”

*Getting used to it, becoming familiar with the children.*

When describing the process of caring, many caregivers articulated that part of what helped them cope was “getting used to it” and becoming more familiar with the children. Participants’ expressions about “getting used to it” seem to refer not only to becoming accustomed to the work, but also accepting difficult aspects of the work, and perhaps accepting that this is just the way it is.<sup>3</sup> Nozuko described adjusting to caring for her son, through her belief in God and through getting used to it.

*I got used to him. So now I enjoy being with him... Eh (unclear) at first, I didn't (unclear) but it's something you get used to when time goes, then you have to accept it. It's a gift from God. Then you have to live with that.*

Nobuhle, a carer at the orphanage, described what it was like adjusting to caring for the children,

*When you start working with children it's not easy, especially caring for the disabled children. But when you get used to them you give them that love and be able to clean them and bring them closer. ... Mama [the centre coordinator] always told us that we must care for them and get used to them, then they will also get used to us. Yes.*

Boniswa, who was a sibling and worked at the orphanage, said, “For me to work here? (...) It's nice, it's nice. Because I've got used to it. Mmm.” Mthetheleli, a father and husband of the orphanage coordinator, also articulated this view, “*I got used to the work we were doing here and I got to see that; bringing these children to our home was actually a good idea. ... No, it was nice, because now we were used to the children.*” Nomlanga, another carer at the orphanage, said, “*Because I wanted this job so, I persevered and got used to it.*”

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<sup>3</sup> It may be that “getting used to it” for participants entailed more than just becoming accustomed to and accepting the work of caring for children with disabilities. In her article entitled ‘*You get used to it*’, Frenkel (2002) describes her reflections while working with trauma burns unit at a children’s hospital in South Africa. Frenkel (2002) posits that for nurses in the trauma unit, “getting used to it” involves forming some kind of defence or protective skin in order to cope with working and being exposed to such trauma every day. Frenkel (2002) describes various defences which nurses may employ in order not to become overwhelmed by the pain and trauma of the children in their care. Unfortunately, I did not ask participants more about what “getting used to it” meant for them, but it is possible that it involved some kinds of defences.

*Perseverance and endurance.*

Nomlanga's words also point to coping through perseverance. She mentioned the importance of perseverance and endurance later in her interview as well.

*Endurance helped me a lot and the person that was here before me just told me not to lose perseverance, be patient and do what I was taught.*

Other caregivers also spoke about the importance of perseverance in coping with caring. Giselle, a mother, explained it in this way,

*Sometimes it is a little bit hard. How do I explain... But if you push through, then you will come out on the other side. One just has to push through and ask for strength and then you will come out on the other side, but it is really difficult to sit with a disabled child.*

Veliswa, a mother, also spoke about the importance of perseverance, when she told me about how she would advise a new parent of a child with a disability,

*I would tell that someone to persevere and be a loving person. .... She must be able to look after her child and just accept the situation. She must love the child all the time knowing that we also have children like that.*

This excerpt from Veliswa's interview also illustrates how some parents found it helpful to remember that there are others who have children with disabilities. This links to the value of connection and social support as coping mechanisms, which is discussed in the next section.

*Social support*

The theme of the value of social support as helping caregivers to cope with caring included subthemes of assistance with caring, connecting with other parents, and processing difficult experiences with others.

a) Assistance with caring, relief work and me-time

Some caregivers also spoke about how other mothers or centres for children with disabilities had assisted them by caring for their children, and providing them with some relief from caring.

Participants spoke about the assistance their families gave them with caring, which sometimes enables them to have much-needed “me-time”. The excerpts in this section illustrate how other people taking responsibility and engaging in the work of care—in other words, how broadening the distribution of care work, was significant in enabling caregivers to cope. Also evident in these excerpts is the extent to which these caregivers usually carry the brunt of caring work.

Pamela, a mother, described how shocked and touched she felt when another woman came alongside her and assisted with caring attentively for her son, giving her a break from caring:

She was just, you see, not all the children, not all the people can just ignore you or just discriminate against your child but you get one or two who loves your child and then the one I took, while working here, she loved my child, and she was not working here. She will say ‘no go to the shop, I will look after your child’. And then I know she will wash after my child. And she will wash my child’s clothes, she will do everything. ... Then it’s whereby I realised that your family can just (sideline you), there are people who are going to look after you. ...

*Interviewer: How did it feel when she was helping you?*

I was shocked, when I opened the door and she was busy washing my child. Was, "Yoh! There is other people who can do, who can wash, who can help me." Then when I said, “No, give him, I will continue with him”. She said, “Nuh uh, I will take care of the child and I will make food, I was busy making food, and I will feed your child.” ... And I was looking at her and thinking that maybe she is going to do it today but tomorrow, not again. Then she looked at me and say “Ah man, don’t worry, go wherever you want to go!”

Some years after this episode, Pamela started the edu-care centre. Funeka, another mother, described how Pamela’s care for her child at the centre—even during holidays—meant that Funeka could attend workshops, which she found helpful:

*What used to help was to go on those workshops... Mama Pamela... She adores children very much, even when the schools are closed and won’t be around you are able to bring your child*

*here, she takes care of them. She has that heart, since she also had a disabled child. Even when it's a holiday she doesn't care, you bring your child.*

Another mother, Jacqui, spoke about the necessity of having relief care for people with disabilities. Jacqui lived in a different area to Funeka, where there was not a centre where she could send her daughter. She spoke about the need for a centre in their community, so that parents could have some relief from care work. Jacqui also described how paying for relief work can be expensive:

*What we actually just really want to have here in our community is that we can open a centre for me that we can uh for the disabled – I mean if- like if we as the parents who want to go to town or somewhere close by then there is (...) people to look after the disabled people. And uh my thing is also that we are here, it is also not that we are too many – we are a few currently but some of the parents' stuff is also that they would also like to also go out, but now there is not one and some of the people even want to be paid, "Give me a R50, give me a R60?" And when they also look at the time when you come back. That [a centre] is what we really – what my desires are here.*

Rachel spoke about how her sister-in-law's family had helped her by taking care of her son, and provided her with much-needed "me-time". They also attended training about how to care for her son:

We had... all the different types of training, there, and it was, it was good moments, but it was also nice. sometimes when you get away from, you need to get some rest away from this child you know, and when you get ah, you know- I'm not heartless when I say "this child", because sometimes they make you so tired, you just want to get away, you know, ah. So when we, when we, sometimes when we had these trainings, neh, now my sister in law, she's passed on now, I would leave him by my sister in law, and then I would go for this training. And it was such a (unclear). When you just away from this child, and, you sit in this class, and you actually have some me-time. Yes, I'm coming to learn more, and I'm gonna have these trainings and stuff like that, but I've got me-time. You know? There's no Brendan that you have to pick up, and you

have to do one, two and three. So that was also, those were good times for me, that was good times. It was empowering, but it was always, it was always, as much as it was empowering, it was also an opportunity for me to rest, you know, just to find my rest in this room, you know. People see like I'm coming to train. Yes, I'm coming to train, and I'm listening to you, but it's a, almost had a two prong, how can I say? Ah, advantage for me. It's like resting and learning.

Robyn, a mother, described how both her family and friends supported her with caring for her son by giving her some time off from caring:

*My mom was really helpful. She has always been there for me, and my sister and most of my family and friends were also there for me. Everyone was there for me. ... They are a lot more available, give a helping hand and they come and fetch him, so I can have a little me-time. They come and fetch him and take him out so that I can have a little self-time for myself. ... I go out, I go and get books for myself so that I can be relaxed for a little while. I just do something for myself I do, I can't now exactly what I'm actually doing something yes. So that I can just for a little while ( ) be relaxed and not think about the situation.... I feel I am more relieved for a little while so that I can rest just a little. Or I just get some sleep in, if I sleep, or if I take a bath or do something. It is just very relieving to not have him with me for little time, it's just a little bit of a relief.*

Giselle spoke about how her husband and mother's family sometimes provide relief care for her child, but also recognised that she does not stay away for long because she worries about her child.

*It is only when my husband takes my child to my mother and them, then I am alone a bit, or if I feel I want to go to my sister for a little while, then he is – if he is not working that day then he will... But otherwise I am here full time. But I also don't stay away long because then I am worried about him.... I won't say they help me a lot, most of the time I am with him. And in the evenings when my husband gets home, then my husband will also help me and so.*

These stories about the role of social support in assisting caregivers to cope with caring illustrates how others' taking responsibility for caring, even for short periods of time, can enable caregivers to recuperate and engage in self-care. Taking care of themselves seemed to be difficult for caregivers, as they carried the brunt of the responsibility and labour of caring for children with disabilities.

b) Connections with other parents of children with disabilities

Another source of support for many of the parents in this study was connecting with other parents of children with disabilities. Rachel articulated how connecting with other parents and networking can be helpful Rachel described how other parents referred her to health professionals who assisted her too.

But then somebody said, it's important for parents to have a supportive place and also to learn a lot from parents. They will guide you, where they did and they got assistance so you will also follow. I think that is why this organization [DICAG] is also a success... it is a haven for parents to come and get some help. ... But I mean, you know... it's important to reach out to other parents so that you as a parent can get that necessary support on this journey, with this child with a disability. ... You talk to parents and you would speak to somebody and say "you know I seen that, I saw an occupational therapist, go to her, speak to her." So somebody pointed me to the occupational therapist. ... Then somebody pointed me to a social worker... Rita Johnson, I will never forget her.

In this excerpt, Rachel also refers to the support other parents can provide in the form of teaching about caring. This theme is further explored in the subsection about learning to care.

Pamela, whose son with a disability passed away, spoke about how interactions with other parents helped her to cope through the time following her son's death.

But my child died at the squatter camp. The sun was so hot at that time, and I couldn't go out, I'll just stay at home, but because of the parents, and say 'Pamela I have this problem. Will you please help me?' Then I said [to myself], "Here are parents, and they need you, I must stand up

and help them.” Yes, I am still helping those parents. And they were also making me strong, saying, “This is not the end of the world. We are here, we need you, and there are other parents.”

Pamela’s story indicates that taking responsibility for helping other parents helped her to “stand up” during a time when she seemed to be grieving for her son and just felt like staying at home.

In addition to articulating the importance of connecting with other parents of children with disabilities, quite a few of the participants in this study spoke specifically about significant other mothers of children with disabilities who had come along side them and helped them to cope with caring for their child. Veliswa articulated another mother’s support as follows,

*She supported me, sat me down while I was telling her about my daughter’s situation. She says; she has a child with epilepsy and the child would be sick the whole day while she was gone for work. And she also told me to look after my child and knowing that I’m not alone. There are many mothers out there who also have children with disabilities.*

Rachel also spoke about another mother who helped her to cope with caring for her son in a significant way,

There was a particular parent ah, Linda, that travelled with car, that travelled with a car [to the parent support meetings]. And then she said, "No, I'll come and pick you up" you know, so, she was, it's a it's a story but it's a, she was very helpful for me. And she also had a child with a disability, you know, but she could drive, and then she would take me, come and pick me up, and she arranged always like, our our, she was very fluent, you know, she was very vocal than what I am that time. ...She was like almost like my- she would assist me, pick me up and, "Come, I'll pick you up" and she asked questions and I would look up to her and I would I would admire and I would like to. I sort of liked the moments when we would drive together you know, and she comes and picks me up. It sort of assisted me to avoid me from going through all that frustrations that I went through, all that discomfort, all that uneasiness that

people looking at Brendan and, you know, so that was a that was a nice story for me because she was very helpful, you know, she almost like helped me through. ...So for me she was, she was, she was more than a comfort, she just assisted me, such a lot. And if you look back she was almost like.... she was a Godsend, you know, to assist me.

Rachel's account seems to portray a deep sense of gratitude for the assistance and coming-along-side of another mother, during a time which was very difficult for her.

- c) Processing and sharing about difficult experiences (include church/counsellor story, the old woman story, and talking to me stories)

Some caregivers also pointed out how talking with somebody helped them to process and cope with difficult experiences. Rachel spoke about how during the time when her son was growing up there were not many counsellors with whom she could speak, but the church provided her with opportunities to process what she was going through,

There wasn't a lot of counsellors out there, you got your counselling at the church. I will speak to a pastor's wife and tell her that is how I'm feeling. There is counsellors at the church. So you have that opportunity to unpack and unload.

Later in the interview, Rachel voiced how talking to someone about her struggles with raising her son helped her to feel supported,

You talk to somebody, you feel better. Many a times I will talk to somebody and ...when I walk away from that woman I feel so much better and so much lighter because it's almost like she is carrying my weight.

Pamela, a mother and centre coordinator, remarked how she sometimes wished that she had family members with whom she could talk about the challenges she experienced with her children. Pamela also referenced that somebody had previously asked her about the challenges she had experienced, but she had not felt ready to talk at that time. In the excerpt below, which was at the very end of the

interview, Pamela voiced these experiences, and expressed how talking and crying during the interview helped her to feel a bit better:

I feel better if I cry, then, because, sometimes I I (...) I can't just keep strong so I can just keep it in my heart I must talk. Then after that I get better because always then when I get problems with my children and then I say, yoh, if I had a brother it would be better, or a sister, I will go and share my problems with that person. My mother died mos, it was years back. It was twenty...2001 or 2002. She knows that I am strong. But I feel better. I feel very better. When that person come here and told that, "I want you to talk about and process your feelings and how do you grow up whatever" I couldn't say anything. I say, "Ah-ah, I was just growing in the right place whatever." I couldn't say what I'm just saying now. But, I just feel that you can't just keep that secrets for long. Yes, when you talk to other people you get better. That is why I say, "No, I'm feeling better now". But, it happens, it happens, but I feel better. Thank you.

Like Pamela, Jacqui, a mother, also spoke about "keep[ing] it in" with regards to not talking about difficult experiences. Jacqui also expressed gratitude for the opportunity to talk and to be heard:

*No I am glad that you came out and asked me asked us a little. Now you see now one feels also a little – there was also someone who talked because otherwise one just keeps it in. Like I just want to cry and now you feel a little free as well. And there are now people that can hear what we talked about disabled children and how it is to have worked with them... No I like to chat and, but I don't like saying a lot about Cindy. It's – it hurts one a little... (...) But thank you very much [laughs].*

Nozuko, another mother, also spoke about the benefit of sharing about her experiences in the interview, and thanked me and the interpreter for the opportunity to talk:

I was suffocating (unclear) At least if you have someone that you can share, it's going to be easier to cope... Thank you for making me talk, because I don't talk easily!

### *Learning to care for children with disabilities*

An important theme relating to care work in the interviews was participants' stories about learning to care. While most participants learned through a combination of methods and experiences, the main three pathways to learning were first-hand experience of caring for children with disabilities, learning from other caregivers, and learning from organisations and institutions.

#### *Learning by first-hand experience.*

Nozuko, a mother, spoke about how through accepting and living with her child's disability, she learned to understand her child's needs, and be able to attend to them.

Yes and when (unclear) when you accept it and you live with it, that's when you can see that you really understand how she grows, what she wants, whenever she needs something you have to understand that she is wet now, she wants you to change this nappy.

Rachel, spoke about how when raising her son, there were some things which she was taught, but there were other things which she just had to learn on her own via trial and error.

I learned by trial and error. There is things that you learn but there is certain things that you just have to figure out for yourself you know.

Mthetheleli, a father and husband of a centre coordinator, spoke about how he and his wife learned to care for children with disabilities by caring for their son, which enabled them to later open the orphanage:

Ok, we learned it from our son and then we decided we should take other kids as well. ... We took children after the passing of our son. Because we knew how to look after a child with a disability, we decided to open this center and by that time, he had passed away already.

Thembi, who was a sibling and worked at the edu-care centre, explained that she knew how to work with children with disabilities because of her experience caring for her brother:

Actually there's nothing unusual to me because I used to have a brother that was disabled, yes. My mother's son. So I actually know how to work with them.

Ndiliswa, who worked at the educ-care centre, chronicled how she had first learned to care for children with disabilities by caring for one of her relatives,

First of all, I've got a cousin brother he's got a boy who live with disability. I started from there to understand the children who live with disabilities, because when the child was in the age of 5 years his mother died. Then my cousin brother used to go to work and leave us with the boy, so I was supposed to take care of that boy, after that I must take him from home to school.

Another of the carers at the edu-care centre, Zimkhitha, described how prior to working at the centre, she had helped Pamela, another mother, to care for her child, and had learned how to care through that process:

There's no problem on my side. I was staying with mama Pamela [pseudonym, centre coordinator] who had a child with disability. Her child was disabled so I used to look after him and change him. She used to leave him to go to DICAG meetings maybe for 2 to 3 days, then I took care of him, bathing him, cooking the right food for him and feeding him. So that is why I don't have the problem looking after the children with disabilities, I am used to them.

Nozibele, who worked at the edu-care centre, described how when arriving at the centre she did not know how to care for the children, but that she learned with time and experience:

At first, I didn't know how to take care of a child but as the time go I had an experience of how to take care of them.

*Learning from other caregivers.*

While learning through first-hand experience was one of the ways which caregivers learned to care, learning from other caregivers was also a common learning pathway for participants. Boniswa, a sibling, spoke about how she and her other siblings had learned to care for their brother by learning from their mother:

It w- it was like a normal thing for us because (...) no matter we just watching TV (or what) he would just have fits then we know, well you would know no matter my mother was not there, at

the time, we were small but we know what to do so that he doesn't hurt himself. Mmm. ... We would just see from our mother and then we can- we were never educated so that a disabled person you must do this- no, we just- we just learn from our mother, and then we hear and she started joining DICAG and she went for workshops and stuff, then we hear oh see (there afterwards, then we learn okay so,) we must do it this way so. Just been helping out.

Rachel gave a detailed account of things she learned about caring from other parents of children with disabilities:

So I've learned a lot through... being amongst parents that has got children with disabilities, and I've also learnt from parents that has been on this road prior to me, you know, and and and that was a good way to learn, from other parents, mmm. What I've learnt from other parents is I I would look, and you would sit and would listen and the parent would say, "My child is doing that and my child" and then you would relate, their child is doing the same like my child, you know. Oh, so you know, then I would ask, "What is the child's disability?" Then they will say, and if they don't know then they will say, "My child"- and then- you almost speak the same language neh- you know, you would say, "My child can't stretch out the hand" or, "My child is just floppy ah" or you know, "I have to lift up my child's head". So you would learn and then you would identify and say, "Ooh but it must be a lot for this parent, she's got the same problem like I've got". So then I would ask her, "So how did you do that, how did you, you know, what are you doing to?" ...And she would share information, so, that is what you learn from parents. we share information, we don't hide information, you know, we will share. And I've learnt, you learn from their experiences. I've learnt from their experiences prior to... Maybe my child is three years old, and their child is twelve years old. So I would learn from their experience. How did your child function when the child was three? You know, when did it get a little bit better? It doesn't totally get better but a little bit better. How did you? What support?

And that is what you learn from parents, sharing information, sharing their experiences, you know, speaking about their home environment. How does the siblings cope? How's your children? How do they, how's your community around you? How do you travel? Are you, are you finding travelling? How do you get to the hospitals? Because sometimes it's difficult for you to get into a taxi with a person with a disability, you know, and and you would learn from parents. How do you cope with with your child in the taxi? Are you also not wanting to go with this child in the taxi? ... So you would learn from parents: How did you handle that situation?

So you learn those little things from other parents, you know, how, the day to day managing a child with a disability. Those day to day experiences, those are the things that you learn from ...from their experiences. So life experiences, you know?

Nomlanga, who worked at the orphanage, detailed how when she first arrived, the centre coordinator, Nobantu, who was a mother of a child with a disability, taught her how to care for the children:

*Mama Nobantu [centre coordinator] a mostly taught me how to look after them because when you never work with children of disabilities you don't know what to do so; she taught me how to change their diapers, bathe them, feed them and when a child cries I must go to him and see what's going on maybe there might be a problem I must not assume he just start being a nuisance.*

Nomlanga also remarked how she and the other caregivers at the centre helped one another as they learned to care:

*It's nice because we teach each other, sometimes you find that if one of us here is new and you notice that person is scared of a situation here maybe because she's not used to be around children who have disabilities so, we try to talk to the person and say just give it some time, you'll get used to them and end up working alone around them.*

*Learning via organisations and institutions*

In addition to learning through first hand experience and from other caregivers, some participants spoke about the roles of organisations and institutions in learning to care.

Some participants, such as Veliswa and Boniswa, spoke about training they received through tertiary institutions. When I asked Veliswa, who worked as a carer at the orphanage, where or how she had learned to care, she spoke about her training at colleges and what she learned there.

*Wow! I have a lot of certificates; I even lost count with them. I went to different schools like Masikhule [Early Childhood Development Centre] and Boland College. ... I learned how to play with children. When children are playing I have to be always around them. I learned how to feed them, how to hold them while feeding them especially when they're still very young. I've also learned the first aid and have the first aid kit as well. ... Yes, there is also training about children with disabilities on how to look after them.*

Boniswa, who also worked at the orphanage, described her extensive tertiary education, including having trained as a teacher and a nurse:

Ah, my- okay. I studied to be a teacher. I have a diploma in teaching. I have a diploma in nursing. ... I have a certificate in business management, and yoh it's a lot of them. Must I name them all? Yoh! [Boniswa laughing.] It's a lot of them. And then I did some short courses also.

When I asked Boniswa what training had helped her the most for working with children with disabilities, Boniswa responded that her nursing training was very helpful:

What has helped me the most for working here? Especially with my nursing. I'm not afraid of anything.

While some caregivers spoke about learning through tertiary education, many caregivers talked about learning to care through training and workshops, many of which were organised by DICAG or one of its affiliated centres.

Mandisa, a mother who ran a centre for children with disabilities in the past, described how her training at DICAG had enabled her to stimulate a child's development who had a speech impairment:

*When I was in training at DICAG, I had a child who had speech impairment and that child left here being able to speak properly because we were taught at DICAG ways of trying the child to talk and right now the child is all grown up. He can speak properly and he's at high school doing very well. ... Her parent still comes to me and thanks me saying, "I still wonder ma Mandisa how you were able to help her gain her speech". I thank the training we had at DICAG, that's where we were taught that when children play even if they fight, we must just let them play because that's how something happen and then a child's speech breaks.*

Pamela described how after attending her first DICAG workshop, she asked for training for how to work with children with disabilities, as she was running an edu-care centre but had no training. Pamela recalled how DICAG sent her for training, which included learning about the value of inclusive education:

Then I went to the workshop and at the workshop I said, 'Joh! It was a lovely workshop'. Then I say I'm very happy to meet other parents who have also disabled children. Then I told them about my centre. ...Then- but I am not trained. I need some training for how to handle, and how to work with these children. Then I have, they have ah they sent me to a training inclusive, inclusion education neh? Inclusive education. It's whereby I was learning more how to work with these children. Then I start, they told us that we must mix the children, so that the able children can learn from the disabled can learn from the able children. And I start there to mix the children. Then I educate, we educate the children and I have today children who are at grade twelve, grade eleven, I have more children who is at schools.

Later in the interview, Pamela spoke about how she felt empowered by DICAG.

I was empowered by DICAG. If it was not DICAG, I wouldn't know anything, but now I am empowered, now it is easy for me to go and empower other parents as well.

Rachel also spoke about the role of Disabled People South Africa (DPSA) and DICAG, in learning about her son's disability. One of the learning tools which she received at workshops was documents to read. Rachel described the practical and helpful advice of someone at one of the workshops, who recommended that Rachel take the time when she goes to the toilet to read the documents from the workshops.

How I learned about disability is through these gatherings, these meetings, of parents that was done through my occupational therapist and other therapists and then also through DPSA organisation I then heard about the organisation [DICAG]. And there I learnt about disability, and what is disability, and what is Brendan's problem, and there, then they would give us little, stack of papers after they'd run the workshop, like you've done now, take you through it, read the paper, and then say, "This is for your reading, whenever you go to the toilet or go wherever and you go,"

Cos they would also ask you, "Do you read?" and if you say "No I don't have time, this child keep me too busy and then my husband and then it's this and it's that" you know so when you- the one lady always she liked to say, "When you go to the toilet you take this with you." If a person told me, go and make this thing, I said, "I don't have time to read this", they say "You going to the toilet?" I said, "Yes". So a person told me that, and it looked funny, but I will do it. People will laugh, because it is a joke. But it's practical because I see they don't have time to read. "Why don't you read? Because it is important to read.!" "No I have to put a nappy on, this child is crying and then I must put- this child doesn't want to drink, because now I must give the child a bottle. I'm struggling with this child. He doesn't want to drink. I don't know how to feed this child. Then the therapist would say "Put the bottle because you are helping the child swallow". ... Eventually the child will learn to suck, you know? And then I would say, "I'm tired, I'm done, I'm finished with this child, this child is sleeping, I'm so tired, I don't have

time to read, I don't want to read." And then she said, "But you go to the toilet, and you sit and you have your number one and number two." It's funny but it's good advice and I will do it.

So you would take any help from anybody, you would take advice from anybody and I would go and sit and I would read and that's the way I really started really getting into documents. I would read a document and I would still run to the toilet now and read because that is my quiet place you know. Nobody bothers me and when you read, "Mommy!", you know, "Mommy!!" You know what I am saying? But when you are in the toilet you can say, "I'm in the toilet, wait till I come out". So for me, you know, so for me that was very helpful you know.

In this story, Rachel also mentioned the role of an occupational therapist. Rachel explained in detail how the therapist helped her learn to help her child to suck on a bottle:

So a therapist, we would get training, basic training in the day care centre they would say, you take the child and you put the bottle and you do this, you must do it constantly. And then the child learns to suck because the child couldn't suck. Now you do and then the child, you have to suck because now that the milk will go and then the child will go, you know.

Other caregivers in the study also mentioned how health professionals had helped them learn to care for their children. Pamela, a mother, recalled how people at the hospital had taught her to feed her child:

And then I sit, and I look, because you must sit down when you feed my child because the throat was small neh, she can't just sluk [Afrikaans: *swallow*] him. Now, I was treating my child like this. I will take a piece of bread and, the hospital told me, I will put the piece of bread and it will follow with tea, and then it will open up, open, and that's whereby my child started eating rice and everything, but the meat I was (grating) the meat so that he can also eat.

Robyn recounted how a social worker had assisted her during the first three years of her son's life, helping her learn to care for him:

It was uh uh what can I say uh almost like a social worker who comes to your house and then she gives you training on how you handle your child, how you can play with him, how you can bath him, how you can give communication. You know almost like from the time he is a baby down to outgrowing it, can come show me, show me how to handle him. So actually it was very good help. But it was only up till three years came and in three years it really helped me a lot.

Because now I can also know okay if he is like this and like that now I can communicate more.

The last source of support for learning which participants mentioned was an international organisation who sent volunteers to work at the orphanage. One of the carers at the orphanage described the assistance from the volunteers as follows:

*We were also taught by the GVI [Global Vision International] on how to look after these children because they know them. ... Yes, they also taught us. They said sometimes children gets tired of staying indoors especially if it's cold inside so; if it's a sunny day we should take them outside with beds in that way they also feel what we feel, a nice weather and when it gets too hot we take them indoors again.*

*Learning needs.*

In their stories about learning to care for children with disabilities, some participants also highlighted their or others' learning needs. Learning needs included skills training for caregivers, information for parents, and awareness and education for community members.

a) Skills training for caregivers

Ndiliswa, who worked at the edu-care centre, articulated the need for better training for the carers at the centre.

*Then also the staff must get better training... The training like how to take care much more with the disabilities.*

Zimkhitha, who also worked at the edu-care centre, spoke about her desire to learn to cook appropriate food for children:

*The only problem I have is that I wish I can get a course so that I can cook right meals for the disabled children. Because you don't cook for children with disabilities the same way you would cook for children without disabilities. Their food is cooked differently. I would like to learn how to cook for them. ... To know that you cook for children without disabilities in this manner, and in this manner for children with disabilities. That's the only thing that I wish for.*

Another edu-care worker and mother, Esihle, specified that she would like to learn South African Sign Language to enable her in her caring:

*I still need to have some more. I got some of the skills that I needed. But I still need some more if they can be available. For example, I still need a Sign Language skill.*

Gloria, who worked at the orphanage, described her and other carers' need for training to learn to care for children better:

Yes, yes, yes. If we can have training like how can we help some children that have difficulty to write, you see but she is not normal, you can she can't hold the pen, she needs time, so I can need training, we need training for the disabled children and the epilepsy children, what to do if the child gets that, the attack, what to do. So it was, I think 2005, so we need more, because when you work with children there is a lot of challenges, we need to be aware of the challenges, we need enough information to save so when we are busy waiting for the mom, is at work, so the boss doesn't allow what to do with the child, what to do with the child now, the child is having a fit now! So what must I do.

Rachel, a mother of a son with a disability who had gone through puberty, expressed her need for training about how to engage with children with disabilities when they reach sexual maturity:

I think that maybe for parents, we need to get advice from the doctors or sex therapist or whatever what do we do in that instances when that children reach that peak, because I am still struggling with that you know

b) Information for new parents

Esihle, a mother and edu-care worker, spoke about the importance of parents' having information about their children's disabilities:

*For example parents should know that, like...sometimes...I don't know how to put it. Like in this way, the other parent does not know the disability of her child is coming from. That's why it is important to explain to her how does it go. Most parents do not know how does a disability issue goes.*

Rachel, also a mother, also advocated for the need for information for parents, and specified how this is a need from the time of children's births:

So, it's important that parents then gets a little bit of a information. A brochure, an information brochure about. Yes you do have this information brochures with the milestones—you never used to get it at the doctors before. Now, yes, after all this awareness raising, you will go to a clinic and you get a looooot of papers that you can see now, you know. But those are the things a package a mother must get when she gives birth to a child with a disability, she must actually get a package to say: What [claps] services [claps] is out there, where [claps] can I go to for help, what [claps] do I do next, after I've come to (...) over my shock. ... Then at least now you need to know, after my shock when I get so my senses, where do I go from here? What is the next thing that you do. So it's important for us to get information I think, information.

c) Awareness and education for communities

Some of the caregivers in this study stressed the need for people who are not familiar with engaging with people with disabilities to learn about disability and become educated. In the previous excerpt, Rachel mentioned that awareness raising was the reason that clinics now provide some information to new parents. Veliswa, a mother and carer at the orphanage, voiced her concern about the need for awareness-raising as follows, giving the motivation that everyone will probably encounter someone with a disability at some point in life:

*Yes, it's important for people to learn how to be around a person who's living with a disability. Because you might not have or know someone who's disable but then you will in life encounter somebody who is disable and not know what to do.*

Boniswa, a sibling and a carer at the orphanage, articulated how she felt that particular attention needs to be paid to educating people in the community who have not been exposed to people with disabilities.

Boniswa also argued that educating the wider community might have positive change:

No, no. I think that people need to be educated and participated. And the other thing is this: I don't think that you just- now, what I see is that all the time that people with disability, they have parents who must go to the workshop. Yes, their parents must come to the workshop, but the parents already they have the child with the disability. We must start educating the ones that don't have a child with a disability, because she might have a child with a disability but her friends don't have a child with a disability, but when she goes to her friend's house she leaves the child at home, (...) you understand? If you start saying to the one with the disability: bring your friend to the workshop, or bring whoever you think will benefit this, from the workshop. Whoever the parents are there with the disability, but you must tell another person also. You understand? Then they can accept- because, if- not- it's useless for- I find it useless educating someone that already knows everything about the disabled child, not, instead of giving education to the one that does know nothing about that. You understand? If for example, the creche that my mother creche- the old building, they busy breaking there, most of their parents (...) said that: no, they'll come back when that creche is finished. They don't want their child to associate with the disabled children. It's not fine, it's not (unclear), but, the children came. They don't want no, this creche I don't want. I want to go to that one Mama Nobantu's [centre coordinator, participant's mother] there. But they said: no, there's nothing- the children said: no! The children are fine, we play with the child- the children have nothing. At first, they were afraid of disabled children. But now, no! They play with them. There's noth- they've known that

there's nothing wrong with the disabled children. Mhmm. That's why I'm saying that you must not educate the ones that have disability, or disabled children, you must educate the ones that don't have at all! Mmm.. We must educate the ones that don't have at all a disabled child, then you will see the difference: the attitude towards the children disabled children.

With reference to the situation that some parents do not want their children mixing with children with disabilities at the orphanage, Mthetheleli, a father and husband of the coordinator at the orphanage, voiced his desire for people to learn how to treat people with disabilities:

*Yes, Mama, I would want people how to treat people who are disable, because some people don't want to bring their children here, they don't want children to be mixed thinking that being disable is contagious, yes.*

### ***Routines of caregiving.***

One of the questions which I asked participants during the interviews related to their routines in every-day life. Many participants gave detailed descriptions of their days, including caring activities they engaged in with children. In this section I describe some of the routines of caregivers.

#### *Mothers of children with disabilities caring at home.*

Thobeka, a mother, spoke about her daily routine. She described how from as soon as she wakes up she starts attending to each of her son's needs, and spends the day cleaning the house, herself, and her son, and attending to his needs:

*When I wake up because that child wear napkin you can do nothing. Now when I wake up first thing that I do I must change nappy, (unclear) wash my hands, I must go and make tea or coffee for him. After that I must make my beds. After making my beds and I wash my hands, after washing my hands, I must make the room clean. But at nine I must make him porridge. After I give him porridge now I must change him the night clothes and put other cloths. Now put him on the wheelchair, and I sweep the room *I make* clean. After cleaning the room I must wash myself, after washing I must make everything clean. Then after that he's on the wheelchair that*

time, after that now that I have clean the room, I must again maybe in dinner time I must give him food that time.

Like Thobeka, Nandipha, a mother, also described her daily routines as involving attending to her child's needs from when she wakes up in the morning. In addition to attending to her son's physical needs like Thobeka described, such as feeding and washing him and changing his nappy, Nandipha also described making efforts to make him happy by putting on music or the television:

*I wake up in the morning and cook porridge for my child, then I feed him, after feeding him I put on the heater and bath him. After bathing him I stretch him because he is very stiff. After stretching him I put on his clothes and nappy because he wears a nappy. After that I put him on the wheelchair, then maybe I will do the dishes, when I'm done with the dishes I'll take him out of the wheelchair and put him on the bed and then again make him porridge and feed him. ... Every time after lunch I change his nappy, (unclear) I'll then again take him from the bed and put him on the chair to watch TV (unclear). He would watch TV or I'll put on some music for him because he loves music very much.*

*When I'm done I then maybe remove him again from the wheelchair, and take him to bed for some more stretches. I then stretch him some more. I stretch him three times a day. I then maybe cook some butternut and mash it in blender and feed him, because he only eats soft food. ... After feeding him his supper, since he is tall and there is no bath I put him on the bed to bath him. I usually take a plastic and put it on top of the bed, take towel and put it on top of the plastic, I then put him on top of that towel and take a dish with soap and water and bath him. I bath him twice a day. I bath him and put on his pyjamas and then he goes to sleep.*

Jacqui, a mother, described how she attends to her daughter each morning, letting her daughter choose when to wake up and when she is ready to be washed and to eat. Jacqui also described giving her daughter cards to play with, which she enjoys:

*No but her time is her time, I let her lie the wholetime. Now I come in, “Cindy it is now this and this time”, I also don’t wake her up. Then I touch and make her feel, “You are awake now”.*

*Then I come in, sit her up straight, first a cup of tea. Now I give her her cards or something that she always loves to play with. Then if she is ready now I wash her, and now I give her food....*

*Yes (sighs).*

Jacqui also spoke about the routine of drying and washing her daughter when her daughter gets her menstrual periods. Jacqui emphasised how early her daughter started getting her period, and how sensitive she is when caring for her daughter in this way:

*Cindy gets her periods from the age of six—from the age of six. Cindy is one that (...) you can see if you dry her or – sometimes she gets pains in the leg, here. Or if you pick her up the wrong way then she gets sore. Now what for me also, now, sometimes I have to pick her up then the arm pinches, I have to carry her in here, then I have to come and lay her down, dry her and wash her. Every time you have to change her at her certain time because of the periods.*

For Nozuko, a mother, a less frequent routine, but a routine none-the-less, was taking her son to his clinic and hospital appointments every year:

*They do understand, neh, because they give him the appointment and it's usually by eleven. So that I could take him with the *bakkie*. So it’s fine there by the clinic because it’s your OT, they are always there and helpful. So I don't take him when I go to *fetch treatment* yes. I take him for a physio at OT. And then I do have appointments to the doctors in the hospital. So that’s when I use the transport, *but I go for the appointment in February, March, June and September. I get doctor’s appointments in February and March, then in September.**

Nozuko’s account of the regularity of visits to clinics and hospitals with her son demonstrates how engaging with health professionals can be a routine aspect of the lives of caregivers.

*Caregivers in the centres.*

Some of the caregivers who worked at the centres described their home-life and work-life routines, while others only spoke about their routines at work.

Veliswa, who was a mother of non-disabled children and an adult daughter with epilepsy, and the coordinator of the orphanage-associated pre-school, described how she first attends to her own children in the morning, and then waits for the children in her pre-school to arrive, and starts attending to them:

*My pre-school is in the yard, so before I open it, I wake up and then get my kids ready for school. Once they're gone for school, I wait on the children to come in and start looking after them.*

Ndiliswa, a carer at the edu-care centre, also spoke about her daily routines of caring for her own non-disabled child, and then caring for other people's children at the centre:

Ok. My normal day in my life is to take care of my child because I am a parent in a young age, so I'm supposed to take care of my child. I'm 32 years... so I'm supposed to take care of him. Ah... coz as a... you are a parent you supposed to look after the children and the needs of children. When they come back from school to support them to do their homework or the staff for school. Then at the very same time you must look after them.

Interviewer: And your day at work?

At work, because I'm working with children who live with disabilities, ah... some of the children are walking, some of them are not walking you supposed take them to the toilet, in the toilet so you supposed to clean then you can put him on the bed. First of all when you are working with children who live with disabilities you supposed to love them to take care of them, then you supposed to understand the children with disabilities. Because sometimes some of the children don't know how to take the spoon and eat, so you supposed to take care of those who are not eating, you supposed to use the spoon on your own to feed them.

One of the participants who worked at the orphanage, Bonsiwa, spoke about how busy her every-day routine at the centre was, attending to various needs:

I basically do everything that needs to be done: looking after children, admin, books, everything. So I cannot say which one I do [laughing]... A normal day for me here, eh: You see today? Every day is like this for me. Every day is very busy. I will come here in the centre, check if—check that the children are alright, give them medication, they that need to be given medication, prepare the classroom for the children before the volunteers come. Then I check if the volunteers come, then I will check that everything is right according to their daily plan. Then I will go to the kitchen, check everything is right. Then I come to the office, do the books, then I have to pick the children to bring them here from the crèche. Then, I have to—eh, it's a lot of things I am doing! That's my day [laughing]!

Boniswa, who was also the daughter of the orphanage coordinators, spoke about how she feels her daily routine is different from that of normal people because her routine always involves caring at the orphanage. She described how even when she had another job working at the Department of Social Development, her daily routine included going to the orphanage after work to assist there, before going home. Boniswa described how her own children also now help out at the orphanage after school, demonstrating how her whole family includes helping at the orphanage in their daily routines:

At the beginning? It was, it was never a problem for me because ( ) it's like a- a- I knew the job that's why, it's basically something we are doing every day, no matter I am not here, no matter at that time I was working at Social Development (....) I used to go to work, come back here, do work here before going home. You never from work, home. Mm mm [shaking head]. It's going to be work, here, home [knocks table for emphasis with each word]. You understand? So it-even now, like my sister, still what my sister is doing now it's work, here, home [knocks the table for emphasis]. He- she don't just go home [knocks table for emphasis]. Mm mm [shaking head]. No, even with my children, you see now, they just get off from the taxi here [knocks

table for emphasis], they know it's here [knocks table for emphasis], then home [knocks table for emphasis]. We never like- for a normal person then you just go home [knocks table for emphasis] - after work then you go home, mm mm [shaking head]. It's never like that.

Interviewer: Okay, so it sounds like your whole family is very involved here?

Yes! Yes yes yes yes yes...

Mthetheleli, Boniswa's father and the husband of the orphanage coordinator, described his daily routine, which included helping to feed the children and attending to other needs at the orphanage:

*I wake up and then feed my chickens. ... During the rest of the day, I would uhm...after my return from feeding my chickens, I would come back to check how are things going here [at the orphanage]. I would ask my wife what needs to be done and then help out especially with the feeding. Disabled children need patience, feeding them takes time and so I help a lot during feeding time.*

Nobantu, Mthetheleli's wife and the orphanage coordinator, chronicled her daily routine at the orphanage, from waking up early and making coffee for herself, the other caregivers, and the children, to bathing and feeding the children during the day, singing with the children in the evening, and preparing for the next day. Nobantu, whose son passed away, included how she loves her work, although it is "heavy" because she thinks about her son when she does it:

I know it's very heavy but I love it, the job. I wake up in the morning at half past three, quarter to four, open the radio, make a coffee, I love it because I think about my son. The caregiver, it comes with the children, as a caregiver, comes with the children, to the children, I make a coffee quarter to five again, no matter not able to drink the coffee, but I must make it and they feel, the feel my hands and lovely, lovely. And we will start half past five. It's a everyday thing.

And in a day by 9 o' clock we make a, what we need make, I don't know, I must think about your question again....While we bath the children the porridge is on low. We make the

porridge and put the porridge it on low. We going to feed the porridge from the big pot. Big pot full or porridge, two plates per child. Or three, because the mentally child, they eat a lot. And only you must know that you are going to sit here or give another one. Take one plate and another one my back is sore because they are feeding. And another one because the child must eat food.

We give them the breakfast, and we give them ten o'clock. At ten o'clock we mix the veg and mashed potatoes. Rice, potatoes, veg, pumpkin, carrots, mixed them together, the soup and a little bit bread, or the meat together and it must be soft food. They eat the soft food. Every day we make a different meals fish, and we make it different. This is at ten o'clock. Lunch time, and we also give those, the problem at lunch time, [unclear], we got to make the bread, the teachers.

At three o'clock clock, the bread and tea and an apple, or others, those at three o'clock, we're going to give them milk, or grated orange, a light thing and we try to wipe them if they wet, we change their clothes.

With supper we start half past three, to make the supper. Or we four o'clock, or quarter past four we start to feed the supper. This is the time we can sit down to quarter past five, six to feed them, after that we change them and we put the radio on, our radio was off and we sing. We sing after that. Only them mentally lady you know that one.

So the day is finished and they sleep, then we start to clean up at night and we prepare the clothes for the morning and the next morning.

Gloria, who worked at the edu-care branch of the orphanage, spoke about the daily routines at the centre, which included prayer and workship, teaching things to the children, playing with the children, and supervising the children to ensure they do not hurt themselves:

During the day we start from 8 o'clock. We put the children together, we gather them in a circle then we do some worship and prayer for them and then we take them from different classes and

then we be with them and then we will start to teach them, look after them. Some of them have medicine, so check and write down those who have medicine and how we are going to give it to them. Then we will give them a snack or lunch then we carry on with the activities.

Interviewer: And what kind of activities do they do?

In the mornings then we'll finish the worshipping and praying, then discuss where we're going to discuss with them the theme of the week. Then what we're going to teach this week. We teach them what is going on about them and then after that we teach them the things, like shapes and numbers, alphabet, making sure that they are writing their names, so we teach them how to write their names. how to write their name, how to use the alphabet, we teach them how to use shapes, like houses, and of what shapes to use. Then they go out and play outside or outdoor activities like jungle gym, ball, skipping ropes, sand or sandpit and water play. So we are there to guide them how or we take them to the ground it's also possibly the centre, the field, so they can be in a big space, running around, playing with hoola hoops, and the balls. And then, after that we come back and they have a snack, we feed those who cannot eat by themselves, like the difficulties, those who have disabilities. They can't eat properly so we do that. Then after that we go inside again to the tables and maybe they were painting, play dough, cut and paste, they learn to hold a scissor, to hold a brush, with our guidance. Then after that they eat their lunch, then after lunch they sing their songs, and stretch their bodies then they sit down for story, I tell them a story, and then the others will rest, go to sleep, and then, every day but the disabled ones they didn't sleep so we carry on with them, we look after them so they're not hurt by things because they walk all over. We will have towels to wipe, because they cannot do things on their own.

These excerpts from participants' interviews portray some of the activities and routines of participants. These activities included attending to children's physical needs, such as feeding the children, changing their nappies, bathing and clothing them, as well as attending to social and psychological needs by

doing activities such as playing with children, educating them, and providing enjoyable stimuli such as music and singing for the children. In these excerpts, many participants also spoke about caring for children with attentiveness to details of caring, such as feeding soft foods which are easier for them to eat, and being patient while feeding children.

### ***Ideas about good care for children with disabilities***

Linked to the idea of competent caring, participants spoke about what they thought good care entails, including necessary virtues for good care, and how they felt children with disabilities should be treated.

#### *Necessary virtues for good care.*

When speaking about engaging with children with disabilities, caregivers spoke about multiple virtues which they felt were necessary for engaging in good care. Articulated in the following excerpts, caregivers spoke about the importance of patience, compassion, gentleness, love, having guts, dedication, passion, and attentiveness.

Veliswa, a mother and orphanage-associated pre-school coordinator, described the necessity of being patient, compassionate and gentle:

*Being someone looking after children with disabilities, needs patience, compassionate and not to be rough with children.*

Nomlanga, who worked at the orphanage, also spoke about the importance of patience and compassion, and mentioned love and being caring as important virtues:

*To them? Hey children of disability what I do to them... treat them well and with compassion, because they have disabilities, they not like me so; my compassion is that they can't do anything for themselves, God created them and so it's my duty to treat them well. ... No, there's nothing much to tell besides the fact that being a caregiver needs patience and love for a child with disability. It needs patience, compassion and caring as well.*

Gloria, who also worked at the orphanage, described the importance of patience in “taking time” when caring for children:

I learn a lot and how to take time to eat, don't say she is full because maybe it is difficult for them to open their mouth, so take time, take time, take time.

Boniswa, also a carer at the orphanage, articulated the importance of “having guts,” so that one does not react in fear or disgust to attending to children's needs:

Yes, a child can cut themselves—I'm not afraid. A child has died—they die here—I'm not afraid. I have to change the nappies—I'm not afraid. And I have to change the periods, for them, though they are lying there—I'm not afraid. So, you just have to. It takes guts, you must have guts to take care of them. So, if you don't have the heart and the guts, and you going to be like, “Yuh,! I don't like blood! Yuhh! Aah! Weehhh!” [makes a disgusted and afraid facial expression]. Eh eh [shakes her head].

Boniswa's reference to the need to “have the heart” links to her statement about the importance of passion and dedication as necessary for caring for children with disabilities. With reference to her own experience, she articulated their importance as follows:

Dedication and passion, you must have. If you don't have, if I didn't have dedication and passion about the job, I wouldn't be here.

When describing the way she instructed new carers at the orphanage, Boniswa stressed the importance of their having passion for the job, not just being in it for the money, so that one responds appropriately to the children:

No, you must understand. And you must have a passion which is not just working for the money. It's not about all the money. To people it's about money, but it's about passion. Because if you don't have the passion for the job you're going to (...) you'll just (...) not be reacting to the children.

Funeka, a mother, described the importance of attentiveness during care. This theme links back to the first stage of caring, and illustrates the connectedness of the different phases of care:

You must not be too busy to take care of your child, you must give him your full attention. If you keep yourself too busy to take care of him you won't understand his needs. You need to have time for your child that is how you will know him.

*How to treat children with disabilities.*

In addition to speaking about necessary virtues for providing good care, caregivers also gave instructions for how they thought children with disabilities should be treated.

- i. Treat children with disabilities the same as non-disabled children

One of the common instructions for good care addressed by participants was the importance of treating children with disabilities the same as non-disabled children. For example, Nozuko, a mother, stated:

You don't have to treat him like he is different from other children. Yes, he is a child. He is not different from others.

Zimkhitha, who worked at the edu-care centre, articulated this as follows:

*First of all a parent needs to accept that her child is disabled. She must treat her like the other kids who are not disabled.*

Thobeka, mother, stressed how parents should treat and love their child with a disability the same as they would a non-disabled child. This included instructing parents to not treat children with pity, and to allow children to do things on their own:

*I can say when you get your child you must be... show him love, love him and treat him as if he is an abled child. Just love him as an abled child and don't feel pity for him allow him to do things on his own. Even if you can reach something ask him to fetch it for you, don't treat him like he can't do anything.*

Thobeka also spoke about how she felt parents of non-disabled children should teach their children how to engage with children with disabilities:

*Ok. I can tell parents of abled children to teach their kids that the disabled children are also human like them. They must teach their kids that the children with disabilities are also like them. They must play with them, so that the children with disabilities can feel that they are also human.*

Like Thobeka, Jacqui, a mother, emphasised the importance of treating her daughter like a normal person, so that she would *feel* a particular way:

*No I treat her like I – a person, treat a normal person. I don't let her feel disabled. She has to feel like us – we who can walk, can talk? The same with Cindy.*

In a similar fashion to Thobeka and Jacqui, Nobuhle who worked at the orphanage, described her concern about treating children in such a way that they do not feel their disability:

*It's fine, but you'll find out that one of them has epilepsy, the other one can't speak, so you must make sure you don't make them feel their condition, you must treat them equally. You play with him and do everything with him and he will also feel fine. Yes.*

Funeka, another mother, also expressed concern about the way a child feels when cared for, and gave recommendations for caring that should make a child “feel welcome.” Funeka instructed that people should not separate children with disabilities or objects which they have used from other people or their associated things. Funeka also emphasised that one should love a child with a disability in the same way that one would love any other child one was taking care of:

*Don't put him aside away from people, those are the wrong things you must not do. You must not put him aside. Maybe because his hand is not functioning properly now you put his dishes aside from the other dishes, things like that. ... No, the only thing is to give the child love like you would to your own child or any other child you take care of. Just give the child love, and then the child will also feel welcome.*

Lulama's guidelines for how caregivers should treat children links to Funeka's utterance about treating a child with a disability as one's own:

*I would encourage her that she must treat a child with disability as her own. You did not ask for a child to be disabled, God just gives you. So just treat him as your own child. So she must take care of him as her own child.*

ii. Show your child love

As illustrated in the previous section, for many participants, the incitement to treat children with disabilities in the same way as non-disabled children included *loving* children with disabilities in this way. Other participants also promoted the importance of loving children with disabilities. For example, a mother, Mandisa stated:

*I would tell these parents to love their children because they just like any other children, God created them like this and it's his will that they're like this.*

Gloria, a caregiver at the orphanage, spoke about the children's need for love, and urged caregivers to love children:

Most of the people they don't understand that the child, they needs the love. You have to give your child love. Especially if you work with disabled children.

iii. Treat children differently according to their different needs

Despite strong exhortations to treat children with disabilities the same as non-disabled children, some caregivers also expressed the view that children with disabilities *should not* be treated in the same way as non-disabled children. For example, Mthetheleli, who worked at the orphanage, reported how he and others introduced new carers to caring for children with disabilities:

*We try to let them know or explain to them that these children have a special need so, it's important to always attend to their needs and not treat them like able bodied children.*

Ndiliswa, who worked at the edu-care centre, reported how she would instruct new carers to care. She referred to caring issues particular to children with disabilities. Ndiliswa also talked about being aware of the different needs of different children with disabilities, and responding to them accordingly:

I'm supposed to talk to her because she's not coming to work with normal children, so she's supposed to understand the disabilities then there is issues that sometimes you can't understand if you didn't work with the disability before. So she's supposed to understand each and every child with disability. Sometimes the other child like to play other one she doesn't want to play, so sometimes you think that one who used to like to play when she doesn't want play you think sometimes she's sick because sometimes she wants, sometimes she don't want.

#### **4. Care-receiving, being responsive.**

Being responsive to children as receivers of care was evident in most of the participants' accounts of caring for children with disabilities. This theme comprised participant stories about relationships, communication, and boundary setting with children; and children's development and emotional responses in response to care.

##### ***Relationships with children with disabilities.***

Many of the excerpts presented already have included references to the love that caregivers had for children with disabilities. Here I present some quotations which illustrate the mutuality of love and affection in relationships between caregivers and children.

In response to my asking about her relationship with the children at the edu-care centre, Nozibele responded,

*They love me and I love them too.*

Replying to the same question, Thembi, who also worked at the edu-care centre, said,

[Sound of smiling with breathing in]. Uh, I dunno, I just, uh, I love them because I have also children. Like we, we have a good relationship.

Zimkhitha, another carer at the edu-care centre, expressed her good relationship with the children from the centre in the following way:

*Even when I see them in the location they are happy to see me and I am happy to see them too.*

Before working at the centre, Zimkhitha assisted Pamela with caring for her son. Describing her own relationship with Pamela's child, Zimkhitha said,

*Although I never had a child I used to love him. He knew that I loved him when I was asked to look after him and we used to get along well*

Gloria, who worked at the edu-care branch of the orphanage, spoke about how she feels she has a loving, mothering relationship with some of the children. Gloria recounted how some of the children want to go to school on a Saturday, because they want to see Gloria and the other carers there:

We are their mothers because the whole day they are with us the others go to their parents, those who have no one for the child when they come back from school, so we are those parents. Then the child goes home and they have no love, so that tomorrow she wants to go to school, because she wants to see us. They want to go school on a Saturday.

Jacqui, a mother, spoke about her relationship with Cindy, and described with laughter how they interact as friends:

*Ai yes [sighs]... Not Cindy. As far as I can say, me and her, we are friends for each other. And she sleeps behind my back. And she also knows Ivango [a TV programme] what, 7de Laan, [another TV programme] loves a lot [laughs loudly]. No she watches here and then I say, "I, I want to sleep," Then she laughs at me. Or she  rubs my head. [laughs more]. Ah yes.*

As alluded to in this excerpt, one of the essential dynamics of relationships between caregivers and children was their communication, which is further explored in the following section.

### ***Communicating with children with disabilities.***

Connected to the theme of being responsive to care-receiver's responses to care, participants talked about how they communicated with children with disabilities, including their role in sending out

messages, and how they tried to understand. The importance of attentiveness in engaging with children's responses is particularly evident in this section.

Nomlanaga spoke about how she tries to understand children's needs, and changes her responses accordingly. Nomlanga also mentioned how she sometimes found it difficult to understand the experiences of children who could not speak, and so asked volunteers at the orphanage where she worked to assist her:

*I try to work with them with an understanding; if a child doesn't want this I know what to give him. If a child doesn't like this or don't want this food then I know I must change it and give something else. ... These children cannot speak, the fact that they can't speak I sometimes finds it challenging to be certain of what they feel or going through so, when I can see that something is wrong or not sure of something I always go and ask help from one of the volunteers.*

Esihle, a mother and edu-care worker, described how she thought people should communicate with children with disabilities:

*You talk to him as you would talk to a child who can speak, because he can hear you and he can also see what you are saying. You also try and use Sign Language.*

Another mother, Rachel, described how she communicates with her son at bath time, using talking and gestures to get the message through:

But now when he gets in the bath I wash him you know. I would say to him, "Brendan, I'm putting your water in." I always speak to him a lot because I believe he—you know that's the way I taught him. So then he will come and I will say, "Come, undress yourself." Now... He can't undress himself but if I pull the pants halfway he will take it further. The message comes, the message comes very slowly. So then the message will come, and then he will, so he will get in the bath now.

Giselle posited that she can understand her son better than others because she is his mother and spends more time, and communicates more with him:

*It's probably because I am his mother, I communicate more with him. I am with him the whole day and his father only comes in the evening. And some weekends his father has to work, and then it is only me. Like sometimes my parents will ask me and then tell me the child showed this and this, then I tell them what he was looking for. I, we don't speak uhm (...) uhm mainstream language with him, I speak as I am speaking to you now. I speak to him like that and he understands me and I understand him. And if he tells me, he wants, he wants that on his table, then I know exactly what I should give him and he laughs!*

***Boundary setting with children with disabilities.***

Setting boundaries with children with disabilities was one of the aspects of caregivers' experiences that linked closely with the responsiveness of children to the care they received.

Ndiliswa, who worked at the edu-care centre, spoke about when she cared for her cousin's son. Ndiliswa described how when she stopped playing with him, he became cross, but eventually understood that she needed to go and make food for him:

*Most of the time she used to play because he cannot walk he uses the chair. So when we stayed with him for a long time I used to take the ball then she supposed to take ball and pass back to me the ball then when I'm off to the... to play with him, he's going to be cross because why you do not want to play now. So I was supposed to carry to play but sometimes I talk to him and understand that I'm supposed to make the food for him.*

Nozuko, a mother, spoke about how she taught her son to listen, and to know when things he does are wrong:

*How to sit, how to play, how to listen because now he knows how to listen. He knows when I am shouting sometimes I need to shout because I want him to know that his thing that he is doing now it's wrong.*

Rachel described how she chose to keep her son inside with the gate closed, in order to protect her son from hurting himself by running into a car.

*Brendan was a very hyperactive...if you don't keep him he would run, and once he run, you you wouldn't be able to catch him. it's like he wanted to - and sometimes it was embarrassing for me, it was like, because you keep the children... Look, I keep Brendan indoors, because I'm worried that he will run, neh? And I'm afraid that he will go and run into a car or something. So the gate will always be closed, and maybe it's damaging to a child, but the gate will always be closed because I'm protecting him, neh? But the moment we outside, it's like, "I've got the space!" [Made a gesture with arms wide open.] You know? So if you leave his hand, he just like run, you know!*

Rachel's story also links to the earlier described theme about difficult choices during caring: Rachel recognises that enclosing her son might be "damaging" to him, but fears that he might hurt himself otherwise should she not keep him indoors.

#### ***Children's development in response to care.***

In their stories about children's responses to care, some participants mentioned how their children had developed in response to treatments or other caring interventions.

Esihle, a mother, spoke about how her child who was deaf received treatment and became able to hear:

*There's nothing else about him, he was just deaf. But he received treatment from the clinic, they gave him hearing aids, so he can hear you now when you talk. They put hearing aids on his ears, so he can hear now.*

Mandisa, another mother, explained how her daughter was now able to walk as a result of many hospital visits:

*So, we came here in Cape Town and I took her to different hospitals... We went up and down these hospitals seeking for help and she finally got it as she's now able to walk even though she's limping and lingering on one of her legs, am not sure which one though.*

Funeka, also a mother, remarked how her son learned many things, including how to communicate his needs, after attending the edu-care centre:

*And when he came here he could not see, we thought she would not even help us. At least she agreed to take him so he started coming here in this crèche. After a while he could say if he needs to go to the bathroom, or he's hungry, and she also taught him many other things.*

Nandipha chronicled how her son was not able to see or hear, but with time, prayer, and her attentive stimulation of his senses, he was able to see and hear again:

*Maybe sometimes the doctor said that the child won't be able to do something, with the help of your prayers he can be able to do it. For example, in my case my son was blind now he can see, he was deaf now he can hear. That is why I pray most of the time. When he came back from [the hospital] and was still blind I used to use a phone with a torch at night, switch it on and do like this... But at first he would not follow the torch with his eyes. But one day I saw him following to the direction of the phone When I move it this side he will follow it. Then I saw that his sight was becoming better. Even when we are sitting I talk to him and say, "Hello! Boy! Yey! yey!" Finally, he heard me clearly his ears worked and he knew everything that was happening in the house and also saw everything. As a result, he notices it when I'm not around. Then when he sees me enter at the door he will jump with joy.*

As well as demonstrating her son's physical responsiveness to care, Nandipha also spoke about the joy her son experiences now that he can see her. I present other caregivers' stories about children's emotional responses during caregiving in the next section.

### ***Children's emotional responses to care.***

In many instances, seeing children's joy brought joy to participants. Nandipha, a mother, explained how she enjoyed engaging with her son. Her description includes many references to his emotional responses, such as his replying by laughing, his happiness, his excitement, how he cries, and his enjoyment of playing:

*The most I enjoy in the work I do? The most I enjoy in the work I do, is the part where I have to stretch him, play with him, and talk to him. He cannot speak, but he hears you when you speak to him. When you talk to him he will reply by laughing. So I always play with him and also my other child would also play with him. We always make him happy by throwing the ball around, when he sees that ball he will get excited by jumping, but he can't catch the ball because his arms are stiff. We will play with him almost the whole day, and also take him for a walk on the wheelchair to see my friend. When we arrive there I let him play with the other kids. He will watch while the other kids are playing because he cannot move, so he will just move his legs and laugh at them when they come towards him. After that I will take him inside the house again. When we arrive inside the house he will cry as to show he is not ready to go inside. Most of the time he likes to play, so he enjoys it when you play with him. If I'm too busy I usually put on some music, then he will be quiet and listen to some music.*

Thobeka, another mother, also spoke about her son enjoying seeing other children, and how this made her feel:

*You see one thing that I can say I feel good about, is when we go out and he sees other children together, he enjoys that very much.*

Boniswa, who worked at the orphanage, articulated how seeing the children happy was her favourite part of the day:

*Favourite part part of the day...hmm. Mmmm! Seeing the children happy is all. As long as the children is happy, that's why we are doing this.*

Nomlanga also illustrated her desire for the children's happiness in the following reflection:

*I always find that I'm the one who stresses about them, thinking whether I did a right thing today. Was I able to make a child happy? When I come tomorrow, will a child be happy to see me?*

The theme of caregivers engaging with and being responsive to children with disabilities as the receivers of care highlights the relational nature of caring, and how a very important aspect of caregivers' experiences was their relationships with the children in their care.

### **Interplay of four elements of care in participant experiences.**

These stories about participants' experiences of caring for children with disabilities have illustrated caregivers' engagement in Tronto's (1993) stages of care and the associated virtues: caring about and being attentive; taking care and being responsible; caregiving and being competent; and engaging with care-receivers and being responsive. As the reader will have noticed, and as Tronto (1993) recognises, there are many connections between the different phases of care, and between givers and receivers of care in participants' stories.

For example, according to participants, being attentive to children enabled caregivers to be more responsive to children's responses, which enabled them to care more competently. In addition, caregivers illustrated how their abilities to fulfill their responsibilities for helping children access support was in part dependent on others, such as government, fulfilling *their* responsibilities to provide that support, and provide accessible transport. In a similar way, some caregivers spoke about how their capacity to competently meet their children's needs was dependent on the government taking responsibility by providing financially in the form of grants for children with disabilities. At the same time, participants alluded to how although the government took responsibility by providing the grant, caregivers still had to take responsibility themselves by actively applying for the grant in order to access that form of support for their children. Also, caregivers' spoke about how their competence for caring for children with disabilities, and care centres' abilities to provide care, was linked to how organisations such as DICAG took responsibility by training caregivers and supporting centres.

Linking to Tronto's (2010) emphasis on the particular and relational nature of care, caregivers' stories also illustrated how the way they experienced different aspects of caring was dependent on dynamics in their relationships with particular others, like those with their children, families,

communities and institutions. In connection with the importance of relationships with children in their care about which participants spoke, caregivers seemed to exhibit Kittay's (2002) concepts of the attitude of care—being invested in the well-being of and having a positive emotional bond with the receivers of care, and the virtue of care—continuing to consistently do the labour of care, even when it is difficult or involves prioritizing others' needs above one's own.

Caregivers also spoke about how their own emotions—such as love for their children and anger towards those who mistreated them, motivated their caring. Caregivers also spoke about when making difficult decisions when caring, they weighed up different factors, which included being logical and being guided by their emotions. This is congruent with an ethics of care which values empathy and emotional responses, in addition to rationality, in moral deliberating (Held, 2006).

A parallel exists between caregivers' attitudes about how to treat children with disabilities, and Kittay et al.'s (2005) description of values associated with care ethics: Participants spoke about the importance of treating children with disabilities the same as non-disabled children, which can be linked to the value of impartiality, a value associated with current dominant moral theories. At the same time, caregivers also articulated the essentialness of attentiveness and responsiveness to the particular needs of children with disabilities—the importance of treating them differently and in ways particular to their needs. Kittay et al. (2005) describe how within care ethics, values such as responsiveness and attentiveness, and attention to particularity are at least as important as values like impartiality.

Caregivers' stories also demonstrated interdependencies of people in their lives: Caregivers spoke about how children with disabilities were dependent on them to meet many of their needs. Participants also talked about how they as caregivers were dependent on friends, family, and crèches to meet their needs for social support and relief from care work, and were dependent on government for financial support. These interdependencies also illustrate the interconnectedness of public and private life, which many care ethicists have strived to bring to light (Held, 2006). As Kittay et al. (2005) argue, paying attention to interdependencies in society brings into focus whose needs are being attended to

and by whom, and creates a space in which a more caring society can be worked towards, by equitably distributing and organising care for everyone in these interdependent networks, including caregivers.

Having discussed the findings from this project, in the following chapter I address some of the limitations of the project, link findings to other South African literature, suggest recommendations, and assess the value of this study.

## **Chapter 6: Limitations, Discussion, Implications, and Reflections**

The research question informing this project was: What are the experiences of caregivers of children with disabilities at DICAG-affiliated centres in the Western Cape? In the previous chapter, I presented findings from the study by discussing participants' experiences of caring for children with disabilities using Tronto's (1993) conceptualisation of care as a framework. In this chapter, I discuss some of the potential limitations of the study, propose implications based on the findings, and reflect on the value of the study for stakeholders involved.

### **Potential Limitations of the Study**

#### **Participant and sample limitations.**

One of the limitations of this study was the small sample size, which consisted of only twenty-three participants. In addition, only one of the participants was male, which limited the data about male caregivers' experiences. However, the existence of only one male carer at the three data collection sites was consistent with other research findings which suggest that there tend to be far more female carers of children with disabilities than male carers in South African communities. The participants in the sample represented a range of ages, but only two South African population and first language groups: Black African, isiXhosa speaking participants, and Coloured, Afrikaans speaking participants. Data from other population and first language groups were therefore not collected.

Because of the sampling procedure of recruiting participants from DICAG-affiliated centres, all the participants in the study had some connection to other caregivers of children with disabilities, and some access to the support offered by the centres and/or DICAG, however limited. This recruitment procedure meant that I did not gather data from any caregivers who were completely isolated from other caregivers and/or the support of the centres and/or DICAG. The challenges, coping mechanisms, training and support opportunities of more isolated caregivers may well differ from the participants in this study. This said, some participants spoke about some of their challenges and experiences from periods before their connection with other caregivers, centres and organisations.

### **Language limitations during data collection and analysis.**

When interpreting the data, it is also important to consider the language dynamics that were involved in the data collection and analysis processes. As described before, participants had the choice to listen to interview questions and respond in their first language, whether in Afrikaans or isiXhosa with the help of an interpreter, which many participants chose to do. While all the Afrikaans-speaking participants and many of the isiXhosa-speaking participants spoke their first language for the entirety of the interviews, some of the isiXhosa-speaking participants chose to speak predominantly English, and switch to isiXhosa when they struggled to express something in English. To me, this code-switching practice indicated the value of providing participants with the option to speak their first language throughout the interviews, as it seemed to facilitate their articulation of their experiences.

While participant responses during the interviews did not seem to be limited due to language constraints, my facilitation of the interviews as the interviewer was limited by the language dynamics. When conducting interviews in Afrikaans, I struggled to maintain flow during the interviews, and referred more often to the interview schedule than when conducting the interview in English, although this improved with time during each interview and with each consecutive Afrikaans interview. During the interviews when participants spoke predominantly isiXhosa and the interpreter was very involved in the conversation, it was also more difficult to facilitate the flow of the interview and probe appropriately. When I read the transcripts of interviews conducted in Afrikaans and isiXhosa, I noticed how my attentiveness to probe specific aspects of participant responses was dampened compared to during predominantly English interviews. Reading the transcripts, there were some instances where I would have liked to ask more follow up questions about particular participant responses. Perhaps an interviewer fluent in the participants' languages might have been able to elicit more or different responses from the participants. Despite the imperfection of the language dynamics during data collection, with the help of the interpreter and the participants, I managed to facilitate the interviews in

such a way that participants shared many stories about their experiences as caregivers of children with disabilities.

The imperfection of transcription processes when converting audio to text was another potential space for error or misinterpretation. Despite having most of the audio files re-transcribed after discovering that the original transcribers were not very thorough, it is still possible that some audio files were incorrectly transcribed, or that important sections of audio were missed due to being marked as “unclear” in the transcripts.

One other language consideration to keep in mind during interpretation of the data, is that many of the excerpts presented in the Chapter 5 are English translations of utterances that were originally in Afrikaans or isiXhosa. Despite having the transcriptions translated by a company specialising in African languages services, it is possible that some of the translations were not accurate. In addition, even the best translations will always only be imperfect representations of the original, and it is likely that some things were lost in this process.

#### **Self-report data as a limitation.**

The fact that the collected data were based only on participants’ self-reports of their experiences is a noteworthy limitation (Swartz, 2014). The versions of reality presented by participants during the interviews were not necessarily the same as they or others would have presented them in other contexts (Flick, 2009). Without verifying the data by other methods, it is not possible to ascertain how closely participants’ accounts were to “reality”, whether due to conscious or unconscious processes of participants (Barker et al., 2002). The participants’ ongoing caregiving responsibilities, the sensitivity of the research topic, as well as expectations of the participants and differences in social group membership, may have influenced participants’ self-reports.

#### ***Limitations of self-report due to participant caring responsibilities.***

Because participants were interviewed at the care centres, it may be that the care centre workers felt distracted during the interviews because of being at work. Care centre workers may have felt

rushed to finish their interviews so that they could get back to their caregiving responsibilities. Parent participants may have felt pressured to return to caring for their children. These factors may have influenced how participants engaged in the interviews, including the lengths of the interviews, and may explain why some interviews were so much shorter than others.

***Limitations of self-report due to sensitivity of research topic.***

Due to the sensitivity of the research topic, including potentially traumatic and/or socially undesirable elements, it is possible that participants omitted some aspects of their experiences when telling me their stories. It is also possible that participants idealised parts of their experiences.

***Limitations of self-report due to expectations and social group differences.***

Because of class, racial, and occupational differences between myself—a middle class white student and researcher, and the participants—black and coloured working class parents and care workers, participants may have felt uncomfortable, pressured, or otherwise motivated to say or not say particular things during the interviews. As I, a university student working with DICAG, told participants that part of the purpose of the study was to support them and their centres, it is possible that participants also filtered their stories because of expectations of assistance.

***Limitations due to my position and experience.***

In addition to the previous point about how differences in my and participants' class, race and occupation, may have limited caregivers' responses during interviews, my particular personal experiences, and my lack of the particular experiences of caregivers of children with disabilities limited the way I engaged with participants, my perceptiveness during interviews, and my perceptiveness and criticalness during analysis and discussion. Because of the empathy I felt for the participants and the ways I connected emotionally with them, as well as my total lack of personal experience of many aspects of their lives, not only caring for children with disabilities, but also living in poor, semi-rural areas and facing or having faced discrimination and/or exclusion due to race, class, language, disability and/or living location in South Africa, I felt long-toothed about being in any way critical of the

participants. While my supervisor provided some insight into perspectives of the data which I had not seen, in part due to my being loathe to be critical, the analysis and discussion were still influenced consciously and unconsciously by my experiences, views and ways of being in the world. With my supervisor's and my own reflections as I wrote up this thesis, and particularly during writing the discussion, I became aware of new ways of thinking about the participants' experiences, added dimensions or complexities in the data which I had not seen before, and avenues of enquiry which may have been fruitful during the interviews but which I did not think of at the time. I incorporated some of these into this thesis, but others will have to wait to be reported on in future publications.

### **Links Between Findings, South African literature, and Ethics of Care**

In this section I outline some of the similarities and differences between findings from this study and those in other South African publications, and make links with ethics of care to provide the foundation for implications in the following section. I discuss how caregivers in this study and others understood and accepted children's disabilities, as well as how participants' engagements with health professionals evoke ideas about dependency and the relevance of ethics of care to contexts in which dependency and relationship are central. The distribution of care work in participants' stories and the South African context, the pertinence of care for caregivers considering these and other findings, and ideas about competent care for children with disabilities are also discussed. After illustrating the centrality of responsiveness to and relationships with children with disabilities in this and other studies, I describe the importance of caring communities in these and other caregivers' lives.

#### **Understanding and accepting children's disabilities**

Like the participants in Mathye and Eksteen's study (2016), some caregivers demonstrated biomedical understandings of their children's disabilities, and/or believed their children's disabilities were God's will. While some caregivers in Mudhovozi et al.'s (2012) spoke about disability as a punishment from God, none of the participants in this study expressed this belief during the interviews. Similarly to a caregiver in another study (De Sas Kropiwnicki et al., 2014), one of the participants

adamantly rejected this notion which her husband had expressed about their child. One of the findings common in other South African studies but not evident in this study, was the belief that bewitchment or curses caused in disabilities. One possibility is that participants did not feel comfortable talking about this with me during the interviews. Another possibility is that this belief is less common in the Western Cape where this study took place, as the other studies all took place in the more northern, more rural province of Limpopo in South Africa (Mathye & Eksteen, 2016; Mudhovozi et al., 2012; Negota & Mashegoane, 2012)

Another facet of participants' understanding and meaning-making was their belief that children with disabilities are gifts from God, a belief reported in a number of other South African studies (Mathye & Eksteen, 2016; McKenzie, 2013; Muthukrishna & Ebrahim, 2014). For some participants, this belief assisted them in coming to terms with and accepting their child's disability, as well as accepting their role as a caregiver for a child with a disability.

### **Disability and dependency**

For some parent caregivers in the study, doctors' emphases on all the things their child would not be able to do stood out in their memories. One doctor's persistent efforts to dissuade a mother from taking her child home to care for him, because he would not be able to do anything for himself, links to the notion of trying to avoid human dependency,<sup>4</sup> an idea propagated by dominant moral theories. The mother's insistence on taking her child home and caring for him despite his inevitable dependency illustrates her acceptance of her child's dependence, her commitment to caring for her child, and her willingness to sacrifice her own independence, at least to some extent, to care for her child.

Dominant moral theories which prize autonomy and independence struggle to provide meaningful guidance in situations like this one, in which inevitable dependence and human

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<sup>4</sup> I do not want to minimise the magnitude of the responsibility and amount of work required for caring for a child with a disability, of which the doctor was probably acutely aware when engaging with the mother in this anecdote, but the idea of a child who is completely—according to the doctor—dependent as undesirable is evident in this story nonetheless, regardless of the doctor's motives.

relationships form the basis of moral decision making (Kittay et al., 2005). An ethics of care brings dependency and relationships into the spotlight of morality, and acknowledges their role in life. Yet, rather than dictating, for example, that all mothers attend to their dependent children's needs regardless of the implications of this on the mother, an ethics of care proposes that we create a society in which both the dependent's needs and the caregiver's needs are met, and that care work is equitably distributed (Kittay et al., 2005). In other words, it is not only or necessarily a particular mother's responsibility to care for a particular child who is dependent. Rather, as individuals *and* as institutions we have the responsibility to ensure that everyone's needs are met in a way that respects and values receivers *and* givers of care, maximises people's functioning in the ways they are able, but does not hide or turn away from people's dependencies (Kittay et al., 2005).

### **Distribution of care**

As in other South African and international literature, in this study women seemed to be responsible for carrying out the majority of care work for children with disabilities (Coetzee, 2016; Kittay et al., 2005). This gender bias was evident in the ratio of female to male participants which was twenty-two to one, and in participants' stories, in which mothers, sisters and other female carers bore the brunt of care responsibilities and work, both in families and at the care centres. Female participants' accounts of rejection and abandonment of children with disabilities by male family members further lends support to the imbalance in the gender distribution of care amongst the participants. It is important to acknowledge that participants also spoke about husbands and brothers who assisted with caring, both by earning money for their families and by engaging in care work to give their wives an opportunity to rest. The experiences of the male participant who participated in caring for his son with a disability and later for children with disabilities at the orphanage is another example of male caregiving. However, these instances of male caregiving were infrequent compared to female caregiving in participants' stories.

These findings about the imbalance in the gender distribution of care, and their congruence with other South African and international research, provide support for the project of de-gendering caregiving, and findings ways to attenuate negative effects of imbalanced care duties on women, in order to create a more just and caring society (Kittay et al., 2005). In their exploratory study about South African men's involvement in various types of care work (though not explicitly involving care of people with disabilities), Morrell and Jewkes (2011, p.22) advocate that,

Men should be encouraged to engage in carework in order to provide support for children, the aged, partners and those in ill-health, to address inequalities in the gendered division of labour and to challenge stereotypes that associate carework with women. ... It is fair that men share the burden of care and support those who need care. ... Thus men's engagement in carework deserves to be an explicit goal of interventions.

### **Care for caregivers**

From an ethics of care perspective, shifting the distribution of who cares to a more gender (as well as race and class) equitable distribution is not sufficient; attending to the care needs of caregivers themselves is also a priority for a caring and just world (Kittay et al., 2005). In *Love's Labour*, Kittay (1999) argues that we have the responsibility and obligation to attend to caregivers' needs as much as we do to the needs of the cared for—in this case, children with disabilities. At times due to the asymmetrical nature of many caregiving relationships in which the receivers of care are often not able to reciprocate, and potentially due to caregivers being unable to attend to their own needs due to being wrapped up in caregiving duties to others, caregivers may often not receive the care that they need (Kittay et al., 2005). Kittay et al. (2005) argue that recognising and attending to caregivers' own needs is a way of honouring the care work that they do, and that ways that they often forgo their own needs for those in their care.

The ways in which many of the mothers in this study prioritised the needs of their children over their own needs exemplifies the phenomena that Kittay et al. (2005) write about. The gratitude and

relief with which participants spoke about people who supported them by caring for them and their children, and provided them with opportunities for “me-time” illustrate the importance of receiving care as caregivers. The value which some participants attributed to being able to process their experiences and be listened to in a caring environment during the interviews also demonstrates their need and gratitude for being cared for. Participants’ references to some challenging experiences also allude to their needs or desire for care. These experiences, which echo experiences of caregivers in other South African literature, include feeling tired (e.g. Mathye & Eksteen, 2016); feeling stressed and frustrated (e.g. Sandy et al., 2013); and feeling unsupported by family or community members (e.g. Mhaule & Ntswane-Lebang, 2009).

This points to the necessity of providing care for caregivers, including attending to their emotional needs, and providing opportunities for respite from care in the form of relief care. In line with Tronto’s (1993) requirements for good care, we not only need to notice, take responsibility, and attend to caregivers’ needs; we also need to engage with caregivers as receivers of care to enquire about their needs and experiences of care, and respond accordingly.

### **Competent care**

Geiger (2012) concludes that receiving care is essential for caregivers to be able to competently care for others. The caregivers in this study had many ideas about what constitutes good care. Virtues such as attentiveness, patience, compassion and responsiveness were amongst participants’ ideas about necessary virtues for good care. The emphasis on attentiveness and responsiveness to the children in their care was something which I did not pick up in the South African literature about caring for children with disabilities, but is congruent with care ethicists’ notions of good care (Kittay et al., 2005; Tronto, 1993).

One of the factors which caregivers in this study emphasised was their appreciation of and need for more information, training, and skills for caring for children with disabilities, in order to provide

competent care. Other South African findings also highlighted caregivers' needs for training, skills and information (e.g. Geiger, 2012; Sandy et al., 2013).

In addition to explicitly talking about some of their needs, some stories about participants' choices of care practices in difficult situations implicitly point to a need for more guidance for caregivers. This links to the ethics of care position that we need to develop principles and educate each other about how to be caring in particular and complex situations in which dependencies and relationships are central (Held, 2006). Dilemmas in caring, and care choices which may seem questionable to onlookers, point to the idea that making an effort to care well is not enough for someone's needs to be met. Care needs to be competent in order for someone's needs to be met, and a part of enabling competent care is equipping caregivers with skills, training, and other support structures.

Such guidance is not only potentially helpful for the receivers of care, but also for the caregivers. For example, stories about the extent to which some mothers prioritised their children's needs, such as sleeping in the same bed as their child, or not leaving their child despite available relief care for their child, raise the question if some care practices are sustainable and healthy for the caregivers as well as the receivers of care.<sup>5</sup>

In addition to requiring information, skills and training, to be able to provide quality care, caregivers in this study and others in South Africa expressed their needs for adequate financial support, equipment, and accessible transport in order to provide for the needs of children with disabilities (Mathye & Eksteen, 2016). In this study, travelling with children with disabilities was a real challenge for participants, and was not only stressful, time-consuming, and at times expensive, but also interfered with their capability to quickly transport their children to hospitals and clinics. Some mothers in this

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<sup>5</sup> I do not wish to judge which choices are healthy or helpful for whom, but I do want to very respectfully raise the possibility that the choices caregivers make are not necessarily always the best choices for themselves or their children, despite their loving and intense demonstrations of commitment to their children.

study, as well as in other South African research projects, explained how caring for their child with a disability put a lot of strain on their family income, as they could not earn due to caregiving responsibilities (e.g. Geiger, 2012; Sandy et al., 2013). Despite the provision of grants for caregivers of children with disabilities, participants in this and other studies said that though grants provided some assistance, this was not sufficient to meet all of their and their children's needs

These trends in South African caregivers' experiences lend support to initiatives to prioritise equipping caregivers to be able to meet their children's needs, by providing training, skills, information, accessible transport, adequate financial assistance, and/or care services to enable parents to earn.

### **Responding to receivers of care**

One of the essential components of competent care according to Tronto (1993), Kittay et al. (2005), and other care ethicists is engaging with and being responsive to receivers of care, which demonstrates the relational nature of care. In this study, caregivers expressed various aspects of their relationships with their children, such as how they set boundaries and their children responded, how they communicated with children with disabilities, and the joy which they experienced in loving relationships with the children in their care. Fostering communication and engagement between caregivers and care-receivers, for example as Geiger (2012) did with caregivers at a centre, seems to be a worthwhile endeavour which enables attentive caregivers to understand the needs of children with disabilities, and foster meaningful relationships with them.

### **Caring communities**

One of the challenges which caregivers in this study and in the South African literature experienced was dealing with stigma, rejection and abuse of children with disabilities in their care (Mathye & Eksteen, 2016; Sandy et al., 2013). While this was traumatic for some caregivers, many participants in this study and in that of Sandy et al. (2013) were inspired to engage in advocacy and awareness in their communities in response to the negative treatment of their children. As in Sandy et

al.'s (2013) study, caregivers in this study expressed feeling empowered to advocate for children with disabilities in their communities. The worry that participants expressed about allowing others to care for their children due to fears about their incompetency, which was also articulated by participants in another study (Elphick et al., 2014), added to participants' insistence on the importance of educating communities about caring for people with disabilities. These findings and links to the literature lend support to encouraging parents and organisations who advocate for people with disabilities, in order to work towards creating caring communities which support people with disabilities and those who care for them.

Another component of creating caring communities is having places of care for children with disabilities. Some of the participants in the study struggled because at some point during their lives there had not been places of care for their children in their areas, similar to the experiences of many others in South Africa (Ben-David & Nel, 2013; Geiger, 2012; Kromberg et al., 1997; Mathye & Eksteen, 2016). Not having child-care centres for children with disabilities means that more responsibility for caregiving lies with primary caregivers, and children do not have access to early childhood development or education.

In this context, participants in this study spoke about how the DICAG-affiliated centres and some schools provided care for their children, and how this benefited their children's development, and provided them with opportunities for relief from caregiving. Similarly to centres described in Geiger's (2012) study, while these centres provide essential services for children with disabilities and their caregivers, centre workers in this study described how they have too few staff, insufficient space, a need for more training. Considering the potential of these centres to positively contribute to the lives of caregivers and children with disabilities, supporting these centres is a worthwhile endeavour. Within an ethics of care framework, supporting and developing institutions such as centres for children with disabilities, is a way of redistributing some of the care responsibilities and work, so that there is more balance in who cares.

### **What are the implications of the findings?**

Having situated the findings in the context of other South African research, and considered the limitations of the study, particularly the small sample size, I present some tentative recommendations based on the findings of this study. While the generalisability of the findings is of course extremely limited, the way these findings mirror other recent South African research outputs lends support to the potential applicability of some of the implications of this study. Besides this, however, recommendations even just for this small group of caregivers may be valuable for the caregivers, their centres and DICAG as a supportive organisation.<sup>6</sup>

### **Recommendations for service provision**

The experiences articulated by participants in this study, as well as those in other South African literature, suggest that government services such as the disability grant, funding for care centres and organisations, and institutional support through health professionals do provide valuable support to some caregivers, children with disabilities, care centres and organisations like DICAG. Yet, many of these stakeholders experience the support they receive as insufficient to meet their needs and those of their children, centres, and organisations. While the following needs and recommendations to attend to them are based only on self-report of the participants in this small study, and while I realise my perspective is limited, I do not have doubts about the sincerity and honesty with which participants expressed these needs, nor their applicability to some other contexts in South Africa based on findings in the literature.

### ***Transport needs and recommendations.***

As one of the participants in this study mentioned, access to transport is essential for caregivers and their children with disabilities to access services such as health facilities, education, and other

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<sup>6</sup> The value of these recommendations for participants, the centres and DICAG may be actualised in the report which I will produce and give to the centres and DICAG. The report will include these recommendations, and findings from the study, and the idea is that the centres and DICAG to use as motivation for accessing services, support, and funding.

forms of support. Many participants in this and other South African studies spoke about challenges with travelling with children with disabilities, including having to use inaccessible and/or unreliable public transport, having to wait many hours for ambulances to arrive, or having to use their limited finances to pay to rent a car to travel with their child, as these participants, and about 70% of South African households, do not have access to private vehicles for transport (Statistics South Africa, 2014a). In addition, caregivers who live in rural or semi-rural areas are likely to experience additional challenges due to less transport infrastructure and further distances to service providers. The additional stress, potentially negative health outcomes for children with disabilities of delayed access to health facilities in emergencies, and restriction of access to services such as education which these transport challenges highlight provide motivation for the development of accessible transport options for caregivers of children with disabilities.

#### ***Financial needs and recommendations.***

Insufficient financial resources was another challenge articulated by these participants, those in other South African studies, and a challenge experienced by many families in South Africa, regardless of having a person with a disability in the family (Department of Social Development, 2012). For caregivers, particular challenges in the context of poverty included not having enough money to pay for things like food and nappies to meet children's basic needs, nor to buy equipment or supplies for children to support their educational and developmental needs, both in homes and care centres. In addition, caregivers also articulated not having enough money to meet their own or other family members' needs, due to the prioritisation and sometimes extra costs of attending to the needs of children with disabilities. Finally, centres not having enough money sometimes meant that they could not employ sufficient staff to care for the children, or could not pay the staff who continued to work there.

Although government funding in the form of grants or centre funds partially assisted various stakeholders in meeting children's needs, most stakeholders felt this funding was insufficient. In

addition, many mothers articulated that due to spending all their time caring for their children with disabilities, they were not able to be employed and earn money, which added to their financial difficulties. For some mothers, abandonment by their partners and/or families meant that they did not have another earner in the household. The importance of the needs of children with disabilities as well as their caregivers and families being met lends support to providing more financial support and/or more physical supplies (such as food, nappies, equipment, etc.) to caregivers of and centres for children with disabilities, and/or to provide other care options for children so that parents are able to earn an income.

### ***Centre structural needs and recommendations***

In addition to needing more financial support, care centres like those in this study and some mentioned in other South African studies (e.g. Geiger, 2012) may need additional support in the forms of more caring staff, such as social workers, physio- and occupational therapists, teachers, and others trained to care for children with disabilities. Centres may also need assistance in accessing land and buildings which can accommodate all the children with disabilities in the pooling areas surrounding them.

### ***Responsibility for caring: when I get old/die***

Providing assistance to care centres for children with disabilities not only has the potential to enhance the educational and developmental outcomes of children, but provides another structure in society, besides the family which takes responsibility and does the work of caring. As many mothers in this study articulated, care centres for children with disabilities provide them with the often much-needed opportunities for doing other necessary tasks for themselves or their families.

Caregivers also expressed the need for individuals or institutions who would assist them with caring for their children when they became old, and after they passed away. The scarcity of people who took responsibility for caring for children with disabilities in these communities highlights the

importance of providing care workers to families, and/or creating caring institutions which care for people with disabilities.

### *Developing competent caregivers and places of care*

While having people and places of care who take responsibility for children and other people with disabilities is essential, the nature of care which they provide is also important (Tronto, 2010). As caregivers in this study spoke about, caring for children with disabilities involved processes of *learning* to care, and not all who caregivers referenced were able to provide good care. In order to enable caregivers to care well, caregivers need to learn skills about caring, such as how to meet the physical and emotional needs of children; learn knowledge about children with disabilities; and be equipped to engage with and respond to children with disabilities, including communicating, setting boundaries and discipline, and dealing with evolving developmental needs of children, such as their sexuality. In addition to these learning needs, caregivers spoke about the importance of fostering necessary virtues of care, such as attentiveness, patience, and responsiveness. The physical environment was also mentioned by participants as important for being able to provide good care: Sufficient space in the centres, and houses which were accessible to children in wheelchairs were cited as vital for meeting children's needs. As Tronto (2010) puts forth, in caregivers, families, and institutions, both the emotional, social and physical dynamics of caring need to be investigated and developed in order for those spaces to provide *good* care. Training health professionals, such as doctors and nurses, to be more aware and better equipped to support caregivers of children with disabilities is another aspect of creating caring institutions, which both positive and negative aspects of participants' stories demonstrate.

Based on caregivers' accounts, personal experience, training workshops, speaking with and learning from other parents and caregivers of children with disabilities, helped participants to learn to care. Fostering these learning opportunities for caregivers may enable them to care more competently for children with disabilities. Supporting organisations such as DICAG who provide training to

caregivers and opportunities for caregivers to learn from each other, and/or organising for other caring professionals to provide training and support to caregivers are possibilities for fostering learning opportunities. Caregivers in this study specifically emphasised the role of DICAG workshops in equipping them to deal emotionally and physically with the responsibility and work of caring for children with disabilities, and supporting such an organisation seems like a worthwhile endeavour.

### ***Care for caregiver: psychological support, respite care***

The emotional, social, spiritual, and physical stresses and challenges which caregivers in this and other studies experienced provide motivation for caring for caregivers. Providing psychological support services, such as counselling or other therapy, may be helpful for caregivers as they deal with caring for children with disabilities in often unaccommodating and unsupportive circumstances. The instances in which participants chose to speak their first language, and particularly when participants switched to their first language to better express themselves, suggest the importance of providing support opportunities to participants in their first language. Providing places and/or people who provide respite care services for primary caregivers is another way to support caregivers, so that they can have opportunities to rest and engage in self-care.

### **Recommendations for activism**

Some of the challenges experienced by caregivers result from uncaring attitudes and responses from families and communities. As caregivers in this study highlighted, advocacy and awareness are essential for changing the attitudes of communities, so that they will be more caring and supportive of caregivers and children with disabilities. Some caregivers also mentioned the importance of engaging in advocacy and awareness with parents of children with disabilities, to enable them to learn and cope with caring for children with disabilities. From this study, and experiences of negative attitudes towards people with disabilities in other studies, there seems to be much need for activism which focusses on increasing awareness and advocacy for people with disabilities and those who care for them, and organisation such as DICAG and other who engage in this work should be supported.

### **Recommendations for further research**

Research in the form of formal needs assessments and service delivery to caregivers of and places of care for children with disabilities may be a good step towards providing evidence for improved service delivery and/or policy changes. Researching caregivers' perceptions and experiences of support services, such as psychotherapy or support groups, may also be an important line of research, to investigate how best to support caregivers as they do their important work. Evaluative research into advocacy and awareness programmes, to find out what kinds of programmes are effective for increasing knowledge of and changing attitudes towards people with disabilities might also be a fruitful endeavour towards creating more caring societies. It may be useful to further explore using an ethics of care framework as a method of analysis as I did in this thesis, to further explore its value and applicability in different fields and types of research. Finally, investigating language practices of transcriptions and translations in research in South Africa may be important. My experience during this project was that the accuracy of transcriptions and translations was frequently much lower than I hoped and expected, even from professional service providers. My impression was that transcriptions and translations are seldom thoroughly checked, and that for whatever other reasons transcribers and translators go about this business in a less than thorough way, regardless of instructions! While I am aware that neither transcription nor translation are straight forward processes with easily definable accuracy outcomes, I think there is need to investigate current practices and develop good practices around these issues, particularly in South Africa where language issues are so pertinent.

### **What was the value of this project? Final reflections and hopes for future.**

By exploring caregivers' experiences at the DICAG-affiliated centres near Cape Town, South Africa, I became aware of some of these caregivers' needs, who might take responsibility and attend to their needs, and how caregivers might be involved in providing feedback about support which is and is not helpful. While the study was limited in various ways, my employment of the methods yielded answers about caregivers' experiences, thereby answering the research question. In gathering data

about various aspects of caregivers' experiences, including challenges, support, thoughts and feelings, I achieved these aims of the project.

The first objective of this research project was to give participants an opportunity to talk about their experiences and needs. While various dynamics limited this to some extents, participants' openness and generosity with which they spoke about their experiences in the interviews illustrates that this objective was at least in part met. A second objective was to create awareness amongst researchers, health professionals and other stakeholders about caregivers' needs and experiences. The extent to which this objective is met will be determined by the circulation of this thesis, that of articles which I write based on the thesis, and based on the circulation of the report which I will give to centres and DICAG to use as motivation for support. In line with this, the third objective was to enable DICAG and its affiliated centres to access funding and support using the report as motivation. The content and persuasiveness of the report, the circulation of the report by DICAG and centres, and the readers' and receivers' responses to the report will determine to what extent this objective is met. Finally, and linking to this, the fourth and most important objective of this research project was to support DICAG, its affiliated centres, caregivers and the children with disabilities in their care.

The extent to which I achieved this objective is partly dependent on the outcomes associated with using the report for accessing support. While the achievement of this objective is therefore in part uncertain and to be determined, some participants' expression of the support of this project to them suggests partial achievement of this objective. For example, as mentioned in Chapter 5, some participants spoke about the therapeutic value of talking about their difficult experiences with me. Some participants also talked about appreciating being listened to, and having their experiences viewed as valuable and communicated to others. Two participants expressed their gratitude about connecting with other caregivers through their involvement in the study, particularly the focus group, as they were less connected than other caregivers prior to this study. When I spoke to Ms Ambrose the DICAG national coordinator at the beginning of the project, she said that she felt that through my increased

awareness about caregivers and people with disabilities through my involvement in the project, she believed that this would do some good towards supporting caregivers and people with disabilities in the way I lived my life in future. Ms Ambrose's assertion about my learning through the project rings true with my experience of becoming more aware and more mindful of many issues regarding caregiving and disability through my involvement in this project:

On the whole, your awareness has been raised around disability and even if you are not a person with a disability, you will always be fighting for persons with disabilities. ... You will always be mindful when it comes to disability. So even if you don't do anything for DICAG, I know when I sit here and I speak to a student or anybody I know that person when they get there, their honours and their masters in their hand they will never forget that organization and they will never forget a person with a disability, you will always be reminded, like I said you do something for that person, with in mind you know that it's because of that organization and that person with a disability that gave me this opportunity to do this and better the lives with and children and persons with disabilities. And not just specifically for DICAG, but on the whole: Be assertive and mindful that this is the new generation, an entire new generation. And whenever we as adults and this we've messed up, you people have to go and make it right, you know. Or what we have done right, you have to stretch it. You have to continue and what we've messed up. This generation will have to clean our mess or strengthen what was nice and what was done.

I am very grateful to DICAG, the participants, my supervisor, and the other stakeholders involved in this project, for the learning opportunities they afforded me. As I will soon be starting training as a clinical psychologist, I feel that my exposure to and engagement with caregivers of children with disabilities increased my awareness of issues related to disability and care in South African societies, but also of issues relating to practices of care and experiences of caring more generally. In this regard, using Tronto's (1993) conceptualisation of care to analyse participants' experiences made me more

aware of the importance, dynamics, and potential challenges of different phases of care, including being attentive to people's needs, taking responsibility, doing care work and caring competently, and engaging with the receivers of care. I felt that this framework, and the ethics of care approach, was helpful in enabling my understanding and learning from caregivers' experiences, and provided me with a language about care, dependency, and responsibility which I find enables me to talk and write more productively about these issues. I hope that in whatever small or large ways, my engagement in this research project, the writing of this thesis and the subsequent articles and reports will provide stimulus for further conversations and actions which promote care, and work towards creating more caring societies.

### **Conclusion**

In South Africa, the government has shown desire to provide care and support for caregivers and children with disabilities, through policy documents which outline many of the support needs described by caregivers in this study (DSD, 2009). However, as described in other South African studies, it appears some caregivers of children with disabilities experience insufficient services and support from government, as well as from their communities. My hope is that through increased service provision, activism, and further research with various stakeholders, including organisations like DICAG, we will work towards developing more caring societies in South Africa in which the needs of caregivers and receivers of care are competently met (Kittay et al., 2005).

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## Appendix A

## Search Strategy for Systematic Literature Review

To explore the child-disability caregiving literature in South Africa, I searched the following databases in October 2016, using EBSCOhost as a platform, the limiters presented in Table A1, and the Boolean search query presented in Table A2:

*Academic Search Premier, Africa-Wide Information, ATLA Religion Database with ATLASerials, CINAHL, E-Journals, ERIC, Health Source - Consumer Edition, Health Source: Nursing/Academic Edition, MasterFILE Premier, MEDLINE, SPORTDiscus, and Teacher Reference Center.*

Table A1

*Database Limiters*

Limitier	Options Selected
Peer-reviewed	Yes
Date limit	None
Abstracts available	Yes
Human	Yes
Language	English, Afrikaans, Zulu (All South African language options)
Exclude Medline duplicates	Yes (CINAHL database, as was Medline searched separately)

Table A2

*Boolean Search Query*

Key Word Category	Synonyms and Related Terms
Caregivers	<b>ABSTRACT</b> (care* OR caring* aide* OR parent* OR nurs* OR teacher* OR educator* OR famil* OR “relatives” OR kin* OR guardian* OR father* OR dad* OR mother* OR mom* OR rear* OR foster* OR sibling* OR brother* OR sister*) AND
Children	<b>ABSTRACT</b> (adolescen* OR baby OR babies* OR child* OR daughter* OR infant* OR learner* OR “new?born*” OR newborn* OR orphan* OR pupil* OR school* OR son OR sons OR student* OR teens OR teenagers OR toddler* OR youth OR youths OR juvenile* OR minor* OR offspring OR pediatric* OR boy* OR girl*) AND
Disability	<b>ABSTRACT</b> (((special* OR complex* OR medical* OR exception* OR longterm OR “long?term” OR limited* OR partial* OR ongoing OR chronic OR abnormal* OR non?normal OR sub?normal* OR persistent OR restricted OR unexplained) AND (complaint* OR need* OR condition* OR function OR health* OR ail* OR illness* OR pain OR sight* OR hear* OR afflict* OR sick* OR headache*)) OR ((learning OR mobility* OR emotional OR behavioural OR psychological OR breathing OR respiratory OR hearing OR intellectual OR cognitive OR mental OR vision OR coordination OR developmental OR physical) AND (difficulty OR difficulties OR defect* OR challenge* OR stunted OR delay*)) OR

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((brain) AND (injur\* OR damage\*)) OR disab\* OR congenital\* OR  
 crip\* OR deaf\* OR debilitat\* OR defian\* OR defici\* OR degenerat\*  
 OR dement\* OR depress\* OR abnormalit\* OR amnesi\* OR amput\*  
 OR arthri\* OR "assistive device\*" OR bedridden\* OR "bed?ridden\*"  
 OR blind\* OR disease\* OR disorder\* OR dyskin\* OR dyslexi\* OR  
 dysmorph\* OR dysphor\* OR dysthemi\* OR dyston\* OR dystroph\*  
 OR encephali\* OR epilep\* OR fragil\* OR fufunyan\* OR fufuyane\*  
 OR fugue\* OR hallucina\* OR handicap\* OR "handi?cap\*" OR hear\*  
 OR impaired OR impairment\* OR incapacit\* OR infirm\* OR injur\*  
 OR invalid\* OR lame\* OR manic\* OR mania\* OR masochis\* OR  
 sadis\* OR nervios OR nightmare\* OR NOS OR opia\* OR opsia\* OR  
 paraly\* OR paretic\* OR parkinson\* OR phagi\* OR phobi\* OR plegi\*  
 OR pnea\* OR praxi\* OR prematur\* OR retard\* OR rubella\* OR  
 sclero\* OR scotoma\* OR seizure\* OR "sleep arousal\*" OR "sleep  
 terror\*" OR somn\* OR spin\* OR stroke\* OR syndrome\* OR thesia  
 OR thyroid\* OR trauma\* OR trem\* OR unfit\* OR unsound\* OR  
 unwell\* OR ventilat\* OR wheelchair\* OR "wheel?chair\*" OR  
 "activities of daily living" OR ADD OR ADHD OR akathisia OR aluro  
 OR Alzheimer\* OR anaemi\* OR anemi\* OR anaphyla\* OR anhedoni\*  
 OR anomi\* OR anorex\* OR antisocial\* OR "anti?social\*" OR anxious  
 OR anxiet\* OR aphasi\* OR aprosodi\* OR ASD\* OR Asperger\* OR  
 asphyxi\* OR asthma OR Ataxia OR Autis\* OR banga OR  
 "benzi?mazurazura" OR binge\* OR bipolar\* OR "bi?polar" OR  
 "Bouffée délirante" OR "brain?fag" OR brainfag OR bulemi\* OR  
 burn\* OR catatoni\* OR "Cheyne?Stokes" OR comorbid\* OR  
 compulsi\* OR convuls\* OR COPD OR "Creutzfeldt?Jakob\*" OR  
 crutch\* OR cyclothymi\* OR cystic fibrosis OR DCD OR deliri\* OR  
 delusi\* OR depersonal\* OR derange\* OR dereali\* OR dhat\* OR  
 diabet\* OR diagnos\* OR dyscalculi\* OR dysreg\* OR ebenzi OR  
 echolali\* OR eczema OR emphysema OR encopresis OR encumber\*  
 OR enuresis OR excoriat\* OR FASD OR fibromyalgi\* OR  
 homebound\* OR "home?bound\*" OR hospice\* OR Huntington\* OR  
 hyperactiv\* OR hypersensitiv\* OR hypoactiv\* OR hypochondria\* OR  
 ICU OR Icythyosis OR ID OR imped\* OR impetigo OR  
 "impulse?control\*" OR infarct\* OR "intensive?care" OR ischemi\* OR  
 jaundice OR kufungisisa OR letharg\* OR malad\* OR malform\* OR  
 malignan\* OR meningitis OR misala OR narcissi\* OR narco\* OR  
 NCD\* OR obes\* OR OCD OR ODD OR "otitis?media" OR palliative\*  
 OR panic\* OR paranoi\* OR PDD OR pica\* OR polio OR Prion\* OR  
 prosthes\* OR PTSD OR retinopath\* OR Rett\* OR rheumat\* OR RLS  
 OR saka OR schizo\* OR "self?harm\*" OR "self?injur\*" OR  
 "sickle?cell\*" OR stutter\* OR "substance?abuse" OR "substance?use"  
 OR tic\* OR Tourette\* OR institutional\* OR mute OR mutism) AND  
**ANYWHERE** "South Africa\*"

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## Appendix B

### Research Ethics Committee: Approved with Stipulations



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#### Approved with Stipulations New Application

03-Jun-2016  
Bingham, Julia JR

**Proposal #: SU-HSD-002118**

**Title: Experiences of caregivers of children with disabilities in the Western Cape**

Dear Ms Julia Bingham,

Your **New Application** received on **04-May-2016**, was reviewed by the Research Ethics Committee: Human Research (Humanities) via Committee Review procedures on **26-May-2016**.

Please note the following information about your approved research proposal:

Proposal Approval Period: **26-May-2016 -25-May-2017**

**Present Committee Members:**

De Villiers, Mare MRH  
Viviers, Suzette S  
Fouche, Magdalena MG  
Hansen, Leonard LD  
Horn, Lynette LM  
Nell, Theodore TA  
Van Deventer, Karel KJ  
Hall, Susan SLC  
Graham, Clarissa CJ  
Lesch, Anthea AM  
Toi, Jerall J  
Frick, Beatrice BL  
Williams, Aden B  
Clarke, Catherine CM

The following stipulations are relevant to the approval of your project and must be adhered to:

**The researcher may proceed with the envisaged research provided that the following stipulations, relevant to the approval of your project are adhered to or addressed. Some of these stipulations may require your response. Where a response is required, you must respond to the REC within six (6) months of the date of this letter. Your approval would expire automatically should your response not be received by the REC within 6 months of the date of this letter.**

**If a response is required, please respond to the points raised in a separate cover letter titled "Response to REC stipulations" AND if**

requested, **HIGHLIGHT** or use the **TRACK CHANGES** function to indicate corrections / amendments of **ATTACHED DOCUMENTATION**, to allow rapid scrutiny and appraisal.

#### 1. PARTICIPANT SELECTION AND RECRUITMENT

1.1) Selection and recruitment processes are clearly described. The researcher has indicated in Section 8.2.2 of the form that participants are subordinate to the person doing the recruitment for the proposed research, but it's not clear that this is the case. Please elaborate on this, or if this is an error, please confirm this in your response letter to the REC. [RESPONSE REQUIRED]

1.2) The method of accessing potential participants from one of the centres is problematic. The researcher plans on getting the contact details of the caregivers from the support centre before the caregivers are even aware of the study. When giving their details to the support centres the carers may not have consented to their information being distributed to third parties and them being phoned by strangers. The researcher is requested to confirm with the centre or the coordinator whether the centre has an existing agreement with caregivers that their details may be shared outside of the centre.

It would be more appropriate for Sandra or the organisers of the respective centres to speak about the research at one of the meetings, and invite potential participants to share their contact details with the researcher. Another option is to develop a flyer with details about the research, which may be distributed by Sandra or the centre organisers at one of the meetings. The participants can then submit a reply slip to the organiser confirming that they want to participate in the study. [RESPONSE REQUIRED]

#### 2. INFORMED CONSENT AND ASSENT PROCESSES AND FORMS

The informed consent process is clearly described. The researcher should be congratulated for her effort in ensuring that the informed consent forms are extremely thorough and easy to understand.

#### 3. SCIENTIFIC VALIDITY/METHODOLOGY/ RELEVANCE

Some subsections of questions listed under the semi-structured interview schedule (see "Centre Background Questions") appear to be a survey-like, requiring one-word or even numerical responses. If this is to be included then it will need to be addressed differently. How will it be tied to a qualitative investigation? How will this data be used, and will it be useful? [Reviewer comment for consideration; response not required]

#### 4. PROTECTION OF DATA, (BOTH PAPER AND ELECTRONIC)

The researcher does not explain how she will store or protect hardcopy data. In the consent form "notes from our interviews" are mentioned, which may need this protection, particularly to protect the continuity of your research. The notes may need to be digitised to ensure that these notes are also stored and protected electronically.

#### 5. INSTRUMENTS (QUESTIONNAIRES, SCALES, and INTERVIEW OUTLINES etc.)

The semi-structured interview schedule is very long (over 60 questions). It's not clear to what extent some of the questions may be possible probing questions. Based on the broad scope of the questions alone, the interview may take more than the estimate of 1 hour to complete. Going over time or running out of time will either potentially inconvenience the participant and or potentially negatively influence the quality of the data.

Please provide a letter of response to all the points raised IN ADDITION to HIGHLIGHTING or using the TRACK CHANGES function to indicate ALL the corrections/amendments of ALL DOCUMENTS clearly in order to allow rapid scrutiny and appraisal.

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

Please remember to use your **proposal number** (SU-HSD-002118) on any documents or correspondence with the REC concerning your research proposal.

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

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

This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki and the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health). Annually a number of projects may be selected randomly for an external audit.

National Health Research Ethics Committee (NHREC) registration number REC-050411-032.

We wish you the best as you conduct your research.

If you have any questions or need further help, please contact the REC office at .

**Included Documents:**

DESC Report

REC: Humanities New Application

Sincerely,

Clarissa Graham

REC Coordinator

Research Ethics Committee: Human Research (Humanities)

## Investigator Responsibilities

### Protection of Human Research Participants

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

1. Conducting the Research. You are responsible for making sure that the research is conducted according to the REC approved research protocol. You are also responsible for the actions of all your co-investigators and research staff involved with this research. You must also ensure that the research is conducted within the standards of your field of research.
2. Participant Enrollment. You may not recruit or enroll participants prior to the REC approval date or after the expiration date of REC approval. All recruitment materials for any form of media must be approved by the REC prior to their use. If you need to recruit more participants than was noted in your REC approval letter, you must submit an amendment requesting an increase in the number of participants.
3. Informed Consent. You are responsible for obtaining and documenting effective informed consent using **only** the REC-approved consent documents, and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Please give all participants copies of the signed informed consent documents. Keep the originals in your secured research files for at least five (5) years.
4. Continuing Review. The REC must review and approve all REC-approved research proposals at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period**. Prior to the date on which the REC approval of the research expires, **it is your responsibility to submit the continuing review report in a timely fashion to ensure a lapse in REC approval does not occur**. If REC approval of your research lapses, you must stop new participant enrollment, and contact the REC office immediately.
5. Amendments and Changes. If you wish to amend or change any aspect of your research (such as research design, interventions or procedures, number of participants, participant population, informed consent document, instruments, surveys or recruiting material), you must submit the amendment to the REC for review using the current Amendment Form. You **may not initiate** any amendments or changes to your research without first obtaining written REC review and approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the REC should be immediately informed of this necessity.
6. Adverse or Unanticipated Events. Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research related injuries, occurring at this institution or at other performance sites must be reported to Malene Fouch within **five (5) days** of discovery of the incident. You must also report any instances of serious or continuing problems, or non-compliance with the RECs requirements for protecting human research participants. The only exception to this policy is that the death of a research participant must be reported in accordance with the Stellenbosch University Research Ethics Committee Standard Operating Procedures. All reportable events should be submitted to the REC using the Serious Adverse Event Report Form.
7. Research Record Keeping. You must keep the following research related records, at a minimum, in a secure location for a minimum of five years: the REC approved research proposal and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence from the REC
8. Provision of Counselling or emergency support. When a dedicated counsellor or psychologist provides support to a participant without prior REC review and approval, to the extent permitted by law, such activities will not be recognised as research nor the data used in support of research. Such cases should be indicated in the progress report or final report.
9. Final reports. When you have completed (no further participant enrollment, interactions, interventions or data analysis) or stopped work on your research, you must submit a Final Report to the REC.
10. On-Site Evaluations, Inspections, or Audits. If you are notified that your research will be reviewed or audited by the sponsor or any other external agency or any internal group, you must inform the REC immediately of the impending audit/evaluation.

## Appendix C

## Letter of Response to Research Ethics Committee Stipulations

05/11/2016

Gmail - Response to REC stipulations



Julia Bingham &lt;jrkbingham@gmail.com&gt;

**Response to REC stipulations**

1 message

Julia Bingham <jrkbingham@gmail.com>  
 To: cgraham@sun.ac.za

Mon, Jun 6, 2016 at 1:27 PM

Dear Clarissa,

Below are my responses to the REC stipulations. Please advise me if there is anything else you need.

Best wishes,  
 Julia Bingham (st.no. 15809846)

**Response to REC stipulations**

Proposal #: SU-HSD-002118

Title: Experiences of caregivers of children with disabilities in the Western Cape

**Researcher responses to all REC points are indicated in blue text. Thank you to the REC for providing useful comments for the research project!**

## 1. PARTICIPANT SELECTION AND RECRUITMENT

1.1) Selection and recruitment processes are clearly described. The researcher has indicated in Section 8.2.2 of the form that participants are subordinate to the person doing the recruitment for the proposed research, but it's not clear that this is the case. Please elaborate on this, or if this is an error, please confirm this in your response letter to the REC. [RESPONSE REQUIRED] In my understanding, it can be argued that the participants are subordinate to the individuals involved in the recruitment as follows:

- a) Sandra, who will initially liaise with the centre co-ordinators to request that the centres participate and find dates that suit them, is the national co-ordinator of DICAG. The centres are in part supported by DICAG, and are affiliated with DICAG. Although I am not certain of the dynamics between the centres and DICAG, it is likely that the centres are answerable to DICAG in some ways. It can therefore be argued that there is a power differential between the national coordinator of DICAG- a national organisation which supports the centres- and those who work at the centres, as the centres are somewhat dependent on DICAG for support and recognition.
- b) The centre co-ordinators will initially inform the centre caregivers about the study, and inform them of when the researchers will be visiting to collect data. At the care centres, it can be argued that the co-ordinators are in a position of power over the caregivers in the centres, and that caregivers are perhaps answerable to the co-ordinators, and therefore are subordinate to the co-ordinators. I do not know the particular dynamics of the centres, but this is a possibility.
- c) Researchers often are perceived as holding power in situations where they collect data, as they have the power to choose what gets reported and how, who is exposed to the collected data and findings, and at times how the data and findings are used. For this reason, and because I and the interpreter will be going to the centres as a part of supporting their parent organisation, DICAG, it can be argued that the caregivers may be perceived or perceive themselves as subordinate to the researchers. However, the caregivers also have the power to choose whether or not to participate, and may not perceive themselves or be perceived as subordinate.

1.2) The method of accessing potential participants from one of the centres is problematic. The researcher plans on getting the contact details of the caregivers from the support centre before the caregivers are even aware of the study. When giving their details to the support centres the carers may not have consented to their information being distributed to third parties and them being phoned by strangers. The researcher is requested to confirm with the centre or the coordinator whether the centre has an existing agreement with caregivers that their details may be shared outside of the centre. It would be more appropriate for Sandra or the organisers of the respective centres to speak about the research at one of the meetings, and invite potential participants to share their contact details with the researcher. Another option is to develop a flyer with details about the research, which may be distributed by Sandra or the centre organisers at one of the meetings. The participants can then submit a reply slip to the organiser confirming that they want to participate in the study. [RESPONSE REQUIRED]

I recognise that the initial plan for accessing potential participants from the parent-support centre is problematic, as explained in the paragraph above. Thank you for bringing this to my attention. With a similar approach to one of the suggestions in the paragraph above, the new strategy for recruitment for the parent-support centre will be as follows: With the permission of the centre co-ordinator, the interpreter and I will attend one of the monthly support meetings and invite participants while there. We will speak about the research project (using the information in the participant information sheet) during the meeting, and invite interested caregivers to either give us their contact details then and there, or contact us directly, or contact us through the centre co-ordinator at a later date. We will then liaise with the interested caregivers to arrange interview times.

05/11/2016

Gmail - Response to REC stipulations

## 2. INFORMED CONSENT AND ASSENT PROCESSES AND FORMS

The informed consent process is clearly described. The researcher should be congratulated for her effort in ensuring that the informed consent forms are extremely thorough and easy to understand.

Thank you!

## 3. SCIENTIFIC VALIDITY/ METHODOLOGY/ RELEVANCE

Some subsections of questions listed under the semi-structured interview schedule (see "Centre Background Questions") appear to be a survey-like, requiring one-word or even numerical responses. If this is to be included then it will need to be addressed differently. How will it be tied to a qualitative investigation? How will this data be used, and will it be useful? [Reviewer comment for consideration; response not required]

I will remove the questions in the "Centre Background Questions" from the semi-structured interview schedule, and include them exactly as they are in a separate document. As noted by the reviewers, these questions are survey-like. I will ask the centre co-ordinator of each centre to answer these questions on a piece of paper, instead of during an interview. The purpose of these questions is to provide some basic data about each centre, which can be used to briefly describe each centre in the reports which I write about them. This data will serve as background data about the centres, while the qualitative investigation will be the focus of the project.

## 4. PROTECTION OF DATA, (BOTH PAPER AND ELECTRONIC)

The researcher does not explain how she will store or protect hardcopy data. In the consent form "notes from our interviews" are mentioned, which may need this protection, particularly to protect the continuity of your research. The notes may need to be digitised to ensure that these notes are also stored and protected electronically.

I will scan and/or transcribe written notes from the interviews as soon as possible after each interview takes place, and store this soft-copy data on my password-protected computer, as with other digital data. Hard copies will be stored in my private office, which no body has access to without my permission.

## 5. INSTRUMENTS (QUESTIONNAIRES, SCALES, and INTERVIEW OUTLINES etc.)

The semi-structured interview schedule is very long (over 60 questions). It's not clear to what extent some of the questions may be possible probing questions. Based on the broad scope of the questions alone, the interview may take more than the estimate of 1 hour to complete. Going over time or running out of time will either potentially inconvenience the participant and or potentially negatively influence the quality of the data.

The semi-structured interview schedule consists of a number of topics (organised by letters, such as "A. *Everyday life working at the centre*", and "B. *Perspectives of children with disabilities*"). I would like to address each topic in the interviews. The questions beneath each topic (which are numbered) will serve as probing questions. Some participants may tell me about multiple topics and address many aspects of each topic without my needing to probe specifically for these. I do not anticipate needing to ask each participant every question, but have included many questions to serve as possible probes for topics.

## Appendix D

### Research Ethics Committee: Approval Notice



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jou kennisvenoot • your knowledge partner

#### Approval Notice

#### Stipulated documents/requirements

29-Jun-2016

Bingham, Julia JR

**Proposal #: SU-HSD-002118**

**Title: Experiences of caregivers of children with disabilities in the Western Cape**

Dear Ms Julia Bingham,

Your Stipulated documents/requirements received on 06-Jun-2016, was reviewed and **accepted**.

Please note the following information about your approved research proposal:

**Proposal Approval Period: 25-May-2016 - 25-May-2017**

#### General comments:

Please take note of the general Investigator Responsibilities attached to this letter.

**If the research deviates significantly from the undertaking that was made in the original application for research ethics clearance to the REC and/or alters the risk/benefit profile of the study, the researcher must undertake to notify the REC of these changes.**

Please remember to use your **proposal number (SU-HSD-002118)** on any documents or correspondence with the REC concerning your research proposal.

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

This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki and the Guidelines for Ethical Research: Principles Structures and Processes 2015 (Department of Health). Annually a number of projects may be selected randomly for an external audit.

National Health Research Ethics Committee (NHREC) registration number REC-050411-032.

We wish you the best as you conduct your research.

If you have any questions or need further help, please contact the REC office at 218089183.

Sincerely,

Clarissa Graham

REC Coordinator

Research Ethics Committee: Human Research (Humanities)

## **Investigator Responsibilities**

### **Protection of Human Research Participants**

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

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

**2. Participant Enrolment.** You may not recruit or enrol participants prior to the REC approval date or after the expiration date of REC approval. All recruitment materials for any form of media must be approved by the REC prior to their use. If you need to recruit more participants than was noted in your REC approval letter, you must submit an amendment requesting an increase in the number of participants.

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

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

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

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

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

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

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

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

Appendix E

Organisational Letter of Permission and Support from DICAG

**Disabled Children Action Group  
( D I C A G )**

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1A TYNE ROAD, WYNBERG, 7800, CAPE TOWN  
Tel: (021) 797 5977 Fax: (021) 797 5077  
E-mail Addresses: [info@dicag.co.za](mailto:info@dicag.co.za)



21<sup>st</sup> March 2016

To The: Stellenbosch University research Ethics Board

Dear Sir/Madam

Thanks for the confidence and the admiration you have towards the work of Disabled Children's Action Group (DICAG).

This letter is just to confirm, DICAG is in agreement with the research project of masters student Julia Bingham, and her supervisor Leslie Swartz , aimed at collecting data on the experience and needs of families in Western Cape communities who have a child, youth with disabilities

DICAG will assist to facilitate access to the [redacted] collection on [redacted] primary, secondary, residential day care centre in Somerset West, Tembinkosi Day Care Centre in Paarl, and Touch Love Parent-Support Centre in Sir Lowry's Pass Village ,

We are sure that this process will benefits both the families, and the work of DICAG.

Thanks once again we look forward to building a relationship which supports the interests of children With disabilities and their families.

Kind Regards

A handwritten signature in black ink, appearing to read 'Sambrose'.

Sandra Ambrose  
National Coordinator  
Disabled Children's Action Group (DICAG)  
1A Tyne Road  
Wynberg  
7800  
Email: [info@dicag.co.za](mailto:info@dicag.co.za) or [sambrose37@gmail.com](mailto:sambrose37@gmail.com)

## Appendix F

Informed Consent Document: English Version

UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
jou kennisvennoot • your knowledge partner**Stellenbosch University**  
**Agreement to Participate in Research Project**  
*Version: English*  
*PI: Julia Bingham, Supervisor: Leslie Swartz***Caregivers of children with disabilities in semi-rural areas near  
Cape Town, South Africa**❖ *Carers at* [REDACTED]

I, Julia Bingham, would like to invite you to participate in my research project. This project is about the experiences of people who care for children with disabilities, which is why I have asked you to participate. I am doing this study as a part of a Master's degree in the Psychology Department at Stellenbosch University, where I am a student.

I plan use the results from this study in a Master's thesis, as well as in articles for publication in journals. I also plan to write a report for your centre, and for DICAG, with whom your centre is connected. This report will describe the study's findings about the experiences of caregivers of children with disabilities in three semi-rural centres in the Western Cape. The report will also include recommendations about the support needs of you as carers, children with disabilities, and the centres. This report may be used by DICAG and the centres to motivate for support and funding.

You were selected as a possible participant in this study because you provide care for one or more children with disabilities, in a rural area in the Western Cape. Importantly, you also work at or attend meetings at one of the following centres which are connected to the Disabled Children's Activist Group (DICAG): [REDACTED]

This document will tell you a bit more about the study, and what we can expect from each other if you choose to participate. At the end of the document, there is a section for you to sign, if you decide you would like to participate. I will give you your own copy of this document to keep, so that you have the information to look at whenever you want to.

**1. Purpose of this study**

The purpose of this study is to find out about your experiences as a carer for children with disabilities in a rural area in South Africa. I am interested in what it's like for you to care for children with disabilities in a day-care centre, your home, and/or your community. I would like to understand what your everyday life is like as you care for children with disabilities. This could include things which are difficult, things which you enjoy, and anything else which is important to you.

After listening to your stories and writing about them in reports and papers, I hope that other researchers, health professionals, and organisations will read them. I hope that other people will understand what it's like for you to care for children with disabilities, what you need to be supported, and what you need to support the children in your care. I hope this understanding will motivate others to support you and your centres as you do the important work of caring for children with disabilities.

## **2. What we can expect from each other**

*If you volunteer to participate in this study, I would ask you to do the following things:*

1. Meet me at the centre where you work or attend parent support meetings at the time that we have arranged. I would like to meet with you at least once, maybe twice, for an individual interview, where we talk about your experiences of being a carer for children with disabilities. The individual interview(s) will be about an hour long, depending on how much you would like to share, and how much time we have together.
2. A few weeks later I would like to meet with you again, to talk in a group with you and the other carers at your centre. At this meeting I would tell you what I understand about your experiences so far. I would also listen to your opinions about what I have said, to check that I have understood you correctly. This would also be an opportunity for you to tell me anything else you would like to add. This group meeting would be about three hours long.
3. Each time we meet, I would like to record our discussions so that I can listen to them again later and write them down. I would ask for your permission to record our discussions with a digital voice recorder.
4. During the individual interviews and group meetings, my research assistant will join us as an interpreter. I speak English and a little Afrikaans, but no isiXhosa. My research assistant speaks isiXhosa and English. If you choose to participate, I would like you to try to work together with my research assistant and I, so that we can understand each other better.
5. The purpose of the study is for me to understand your experiences of caring for children with disabilities. Therefore, if you take part in this study, I would like you to describe your experiences to me and help me to understand what this part of your life is like.
6. If you choose to participate, I also ask you to tell me when you do not understand, or when you disagree with what I have said.
7. I would also expect you to tell me when you do not want to answer a question—that is okay!
8. Very importantly, I would want you to tell me when you feel uncomfortable or upset. Please tell me when you would like to pause or stop the interview for any reason at all.

## **3. Possible risks and inconveniences for you**

If you participate in this study, I would ask you to travel to your centre to meet with me two or three times over one or two months around the middle of 2016. Altogether this will take about five to six hours of your time, plus the time it takes you to travel there and back. I would try to find times to meet which are convenient for you, so that our meeting does not put unnecessary stress on you or others in your life. I would try to arrange for our meetings to be in a quiet, private room in the centre, so that you feel safe when we talk. I hope that the interpreter will help you to feel more comfortable to communicate in your own language.

We might talk about some experiences which are difficult for you, or make you feel uncomfortable. If this happens, please tell me. We can pause or stop the interviews at any time. If you feel upset by any of our meetings, and would like to talk to a psychologist or counsellor about this, I would like to

support you. You can contact Welgevallen Clinic, in Stellenbosch, for an appointment, where you can see a psychologist for free.

- *Phone:* 021 808 2696,
- *Address:* Welgevallen Community Psychology Clinic, Welgevallen House, Suidwal Street, Stellenbosch
- *Email:* [WCPC@sun.ac.za](mailto:WCPC@sun.ac.za)

If Stellenbosch is too far for you to travel, I can help you find a psychologist or counsellor who is closer to you. You can have up to ten sessions which I will pay for. You can find my contact details in Section 8 below.

It is very important to me that I respect and protect you while we do this project together. Please tell me when there are things I could do differently to make you more comfortable.

#### **4. Possible benefits for you and others**

There are no definite benefits for you if you choose to participate in this study. However, there are a few potential benefits, which I hope will be outcomes of your participation:

- ❖ I hope that you will enjoy the process of participating in this project.
- ❖ I hope you will feel satisfaction as you tell me, and thereby inform others, about what it's like to care for children with disabilities in rural areas in South Africa.
- ❖ I also hope that the report which I write based on your experiences, will help DICAG and your centre to access support and funding.
- ❖ I hope that this support, in whatever form, will make your life and the lives of your children better.
- ❖ I hope the report will inform governments and other organisations about your needs, and that this will motivate them to support you and your centre in the important work that you do.
- ❖ I also hope that the findings from this research will add to other researchers', health professionals', and others' understandings of the valuable and complex work which you do as a carer for children with disabilities in rural South Africa.

#### **5. Payment for participating**

You will not receive payment for participating in this study. However, each time you travel to the centre to meet with me for the study, I will give you R50 cash to contribute to your travel expenses. At our first meeting, I will also give you a blanket as a thank you gift, as I am very grateful for your participation.

#### **6. Keeping your information confidential**

Any information from this study that could be connected to you as an individual will remain confidential, and will be shared with others only with your permission, or if required by law. Confidentiality is a form of privacy. Confidentiality means that other people who read reports and articles about this study will not know who the individuals were who participated. They will only know some of the things which the participants said, and some general details such as their age, gender, and language. I will try to keep your identity private by using a false name for you when I write about what you have said. If you would like to, you can choose the name you would like me to use when I write about you and your experiences.

I will keep the audio recordings and notes from our interviews and meetings on my computer, which is protected by a password. I will do my best to make sure that nobody else has access to the written notes that I make, by keeping them in a file. I will also type up the recordings of our meetings so that I have a written version of them. I will also keep this on a password-protected computer. Besides me, the interpreters who help me, and my supervisor, will also see and listen to material from our meetings, because I need their help to understand and make sense of the interviews. My supervisor's name is Leslie Swartz, and he is a professor at Stellenbosch University.

As a part of trying to understand your experiences, I will listen to and read these accounts a few times, and will try to sort what I hear into themes, or groups of experiences which seem to fit together. When we meet at the group discussion, I will tell you about these, and ask what you think about them, and if you think I should change them.

Once I write my Master's thesis for the university, the report for DICAG and your centres, and the articles for journals, other people will be able to read about your experiences, although they will not know your real name. It is possible, however, that people in your community might be able to identify you in the report, since your community is quite small, and people might be able to guess from the small details who you are. To add to this, when we meet in the group meetings I will ask everyone in the group not to share information from in the group outside the group. However, if group members do not listen to this, there is a risk that your identity and experiences could be shared with others. Unfortunately, this is not in my control, but I will do my best to encourage everyone to keep each other's identities and experiences confidential.

If at any point you would like to read or listen to anything that I have written, or the recordings of interviews, you are welcome to do so. Please feel free to contact me (see Section 8)!

## **7. Participation and withdrawal**

You can choose whether to be in this study or not. If you volunteer to be in this study, you can always change your mind and withdraw without any negative consequences. You may also refuse to answer any questions you do not want to answer, and still remain in the study. You will still receive the travel allowance of R50 if you decide during an interview that you want to stop participating. If I think it is in your or another person's best interest, I might ask you to withdraw from the research project—but this is unlikely.

## **8. How to contact the investigators**

If you have any questions or concerns about the research, please contact me, Julia, or my supervisor, Leslie:

- Julia Bingham, the principal investigator: 0765692518 or [jrkbingham@gmail.com](mailto:jrkbingham@gmail.com)
- Leslie Swartz, my supervisor: 0218083446 or [lswartz@sun.ac.za](mailto:lswartz@sun.ac.za)

## **9. Rights of the participants**

You can change your mind about participating at any time, without it influencing you negatively in any way. Participating in this study does not affect any of your legal claims, rights or remedies. If you have questions about your rights as a research participant which neither Julia nor Leslie can help you with, you can contact the Division for Research Development at Stellenbosch University:

- Ms Maléne Fouché: 021 808 4622 or [mfouche@sun.ac.za](mailto:mfouche@sun.ac.za)

**10. Signatures, permissions, and agreement to participate**

If you decide you would like to participate, you can sign this document, to show that you are aware of what the study includes, and that you give permission for the information to be used in the ways outlined in the document. I will keep the copy that you sign, and give you your own copy to keep for future reference.

<b>Signature of Research Participant</b>
--

By signing below, I confirm that the information above was described to me by Julia Bingham in [*Afrikaans/English/isiXhosa/other*] and that I understand this language, or it was satisfactorily translated to me. Julia gave me the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby agree voluntarily to participate in this study. I have been given a copy of this form.

\_\_\_\_\_  
**Name of Participant**

\_\_\_\_\_  
**Signature of Participant**

\_\_\_\_\_  
**Date**

<b>Signature of Investigator</b>
----------------------------------

I, Julia Bingham, declare that I explained the information given in this document to \_\_\_\_\_ [*name of the participant*]. [*He/she*] was encouraged and given ample time to ask me any questions. This conversation was conducted in [*Afrikaans/\*English/\*Xhosa/\*Other*] and [*no interpreter was used/this conversation was translated into \_\_\_\_\_ by \_\_\_\_\_*].

\_\_\_\_\_  
**Signature of Investigator**

\_\_\_\_\_  
**Date**

## Appendix G

Informed Consent Document: Afrikaans Version

UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
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**Universiteit van Stellenbosch**  
**Inwilliging om deel te neem aan navorsing**  
*Afrikaanse weergawe*  
*HN: Julia Bingham, Studieleier: Leslie Swartz*  
*Vertaler: Anzel Rheeder*

---

**Versorgers van kinders met gestremdhede in plattelandse gebiede in die Wes-Kaap**❖ *Versorgers by* [REDACTED]

Ek, Julia Bingham, nooi u graag uit om deel te neem aan my navorsingsprojek. Die projek fokus op die ervaringe van mense wat vir kinders met gestremdhede sorg, vanwaar die belangstelling in u as deelnemer. Ek doen die navorsing, ter gedeeltelike voldoening aan die vereistes vir die Meesters graad by die Sielkunde Departament by die Universiteit van Stellenbosch, waar ek tans 'n student is.

Ek beplan om die data verkry vanuit navorsing te gebruik vir my Meesters tesis, sowel as vir die moontlike publikasie van artikels in joernale. Ek beplan ook om 'n verslag te skryf vir jou sentrum sowel as vir DICAG, met wie die sentrum 'n verband het. Die verslag sal die studie se bevindinge beskryf aangaande die ervarings van die versorgers van gestremde kinders in die drie plattelandse sentrums in die Wes-Kaap. Verdere aanbevelings rakende die behoefte aan ondersteuning vir versorgers, gestremde kinders asook sentrums sal in die verslag weergegee word. Die verslag kan deur DICAG en betrokke sentrums gebruik word as motivering eksterne motivering en befondsing.

U is gekies as 'n moontlike deelnemer vir die studie omdat u een of meer kind het met gestremdhede gestremde, in 'n plattelandse gebied in die Wes- Kaap. Vernaam werk u ook, of woon u vergaderings by, by een van die volgende sentrums wat verbind word aan die Disabled Children's Activist Group (DICAG): [REDACTED]

Hierdie dokument sal u meer vertel van die studie en wat van mekaar verwag kan word, hetsy u besluit om aan die studie deel te neem. Agteraan die dokument is daar 'n afdeling wat u moet teken, indien u besluit om aan die studie deel te neem. Ek sal vir u 'n afskrif van die dokument gee sodat u alle informasie byderhand het.

**11. Doel van die studie**

Die doel van die studie is om u ervarings as 'n versorger van kinders met gestremdhede in 'n plattelandse gebied in Suid- Afrika te ondersoek. Ek stel belang in hoe u dit ondervind om vir die kinders met die gestremdhede te versorg by die dagsorgsentrum, u huis of/en u gemeenskap. Ek sal graag wil verstaan

hoe u alledaagse lewe is terwyl u sorg vir kinders met gestremdhede. Hierdie kan dinge insluit wat vir u moeilik is, dinge waarvan u hou, en enige iets wat vir u belangrik is.

Wanneer ek klaar na die verskeie stories geluister het en daarvoor gerapporteer het in artikels, hoop ek dat ander navorsers, gesondheidspraktiseerders en organisasies die resultate sal lees. Ek hoop dat ander mense sal verstaan hoe u dit ondervind om vir kinders met gestremdhede te versorg en verstaan dat u ondersteuning benodig, vir u self asook om vir die kinders met die gestremdhede te versorg. Ek hoop die insig sal ander motiveer om u en u onderskeie sentrums te ondersteun, siende dat u die noodsaaklike werk doen deur die kinders met die gestremdhede te versorg.

## 12. Wat ons van mekaar kan verwag.

*Indien u vrywillig besluit om aan die studie deel te neem, sal ek die volgende aan u vra:*

1. Om my te ontmoet by die sentrum waar u werk of om ondersteuning groepe vir ouers by te woon in die tydsgleuf wat ons afgespreek het. Ek sal verkies dat ons tenminste eenkeer, selfs tweekeer ontmoet vir 'n persoonlike onderhoud, waar ons sal gesels oor u ervaringe as 'n versorger vir kinders met gestremdhede. Die individuele onderhoud(e) sal omtrent 'n uur duur, afhangend van hoeveel u wil deel rakende u ervarings en hoeveel tyd om saam het.
2. 'n Paar weke na die individuele onderhoud(e), sal ek u graag weer wil ontmoet om in groepsverband met u en die ander versorgers by die betrokke sentrum te gesels. Tydens die ontmoeting sal ek u vertel wat ek tot dusver verstaan van u ervaringe as versorges. Ek sal ook dan na julle kommentaar en menings luister oor wat ek sê en verstaan om te verseker dat ek julle reg verstaan. Hierdie ontmoeting sal ook vir u die geleentheid skep om vir my enige iets te vertel wat u moontlik nog wil bylas. Die samekoms behoort so drie ure te duur.
3. Tydens elke ontmoeting sal ek graag met u toestemming ons gesprekke wil opneem met 'n bandopnemer. Die rede hiervoor is sodat ek weer na hulle kan luister en neerskryf.
4. Gedurende die individuele onderhoud(e) asook die groepsvergadering sal my navorsingsassistent die rol as tolk oorneem. Ek praat slegs Engels en 'n bietjie Afrikaans, maar geen isiXhosa nie. My navorsings assistent praat Engels en isiXhosa. Indien u kies om deel te neem, versoek ek dat u asseblief probeer om saam met my navorsings assistent te werk sodat ons mekaar beter kan verstaan.
5. Die doel van die huidige studie, is vir my om u ervarings as 'n versorger van kinders met gestremdhede te verstaan. Ek vra dus, dat indien u besluit om aan die studie deel te neem, u, u se ervaringe vir my sal beskryf en my help om te begryp hoe hierdie aspek van u lewe is.
6. As u kies om deel te neem aan die studie, vra ek u om my te sê wanneer u iets nie verstaan nie of wanneer u nie saamstem met wat ek sê nie.
7. Ek wil ook hê dat u die vrymoedigheid moet hê om vir my te sê as u nie 'n vraag wil beantwoord nie.
8. Dit is van groot belang dat u vir my sê wanneer u ongemaklik of omgekrap voel. Sê asseblief vir my as u verkies om 'n breuk te vat van die onderhoud of om die onderhoud heeltemal te stop.

## 13. Moontlike ongerief en risiko's wat jy kan ervaar

As u aan die studie deelneem sal ek van u verwag om twee of drie keer oor die tydperk van een of twee maande na u betrokke sentrum te gaan om met my te ontmoet. Dit sal in rondom by die middel van 2016 wees. Die ontmoetings sal in totaal ongeveer vyf na ses ure van u tyd in beslag neem, plus die tyd wat dit u neem om na en van die sentrum te reis.

Ek sal probeer dat die tye wat ek reël om met u te ontmoet, vir u gemaklik sal wees, sodat ons ontmoetings nie onnodige druk op u of ander mense in u lewe plaas nie. Ek sal probeer om te reël dat ons vergaderings in 'n stil en private kamer in die sentrum plaasvind, sodat u veilig en gemaklik voel wanneer ons praat. Ek hoop dat die tolk se teenwoordigheid u meer gemaklik sal laat voel om sodoende in u eie taal te kommunikeer.

Ons kan miskien oor sekere ervarings gesels wat u ongemaklik laat voel, of moeilik is om oor te gesels. Indien dit gebeur, sê vir my asseblief. Ons kan enige tyd 'n breuk van die onderhoud vat, of die onderhoud stop. As u omgekrap voel weens enige van ons vergaderings, en graag met 'n sielkundige of berader daarvoor wil gesels, sal ek u graag wil ondersteun. U kan die Welgevallen Kliniek in Stellenbosch kontak, waar u gratis 'n sielkundige kan sien.

- *Tel: 021 808 2696,*
- *Adres: Welgevallen Gemeenskapsielkunde Kliniek, Welgevallen Huis, Suidwal Straat, Stellenbosch*
- *Email: [WCPC@sun.ac.za](mailto:WCPC@sun.ac.za)*

Indien Stellenbosch vir u te ver is om na te reis, kan ek u help om 'n sielkundige of berader te vind wat nader aan u praktiseer. U kan tot en met 10 sessies hê, waarvoor ek die onkoste sal dek. U kan my kontakbesonderhede in Afdeling 8 vind.

Dit is van belang dat ek u respekteer en beskerm terwyl ons saamwerk aan die projek. Vertel my asseblief as u voel daar is iets wat ek anderste kan doen om u meer gemaklik te laat voel.

#### **14. Moontlike voordele vir u en ander**

Daar is geen definitiewe voordele vir u geïdentifiseer indien u kies om aan die studie deel te neem nie. Daar is wel 'n paar moontlike voordele, wat ek hoop u sal ondervind aan die einde van u deelname:

- ❖ Ek hoop dat u die proses en deelname van die projek sal geniet.
- ❖ Ek hoop dat u 'n gevoel van tevredenheid sal beleef wanneer u my vertel van u ervarings, en sodoende ander inlig oor hoe dit is om vir kinders met gestremdhede te sorg in plattelandse gebiede in Suid-Afrika.
- ❖ Ek hoop ook dat die verslag wat ek skryf, gebaseer op u ervarings, DICAG en u sentrum sal help om toegang te kry tot befondsing en ondersteuning.
- ❖ Ek hoop dat die ondersteuning wat julle ontvang, in watse vorm ookal, u lewe asook die lewens van die kinders sal verbeter.
- ❖ Ek hoop dat die verslag die regering en ander organisasies sal inlig oor u behoeftes en dat dit hulle sal motiveer om u en u sentrum te ondersteun met die belangrike werk wat u doen.
- ❖ Ek hoop ook dat die bevindinge van die betrokke studie 'n bydrae sal lewer tot ander navorsing, gesondheidspraktiseerders en ander se begrip rakende die waardevolle en komplekse werk wat u verrig deur kinders met gestremdhede van plattelandse gebiede in Suid-Afrika te versorg.

#### **15. Betaling vir deelname**

U sal nie betaling ontvang vir u deelname aan die studie nie. U sal wel R50 kontant ontvang (as reis toelaag) elke keer wat u na die sentrum reis om met my te vergader. Met ons eerste ontmoeting sal ek vir u 'n kombers gee as 'n geskenk om dankie te sê, asook om my dankbaarheid te toon vir u deelname.

## 16. Vertroulikheid van jou informasie

Enige informasie van die studie wat direk met u as individu verbind kan word, sal vertroulik gehou word en sal slegs met ander gedeel word indien ek u toestemming het, of indien wetgewing dit vereis. Vertroulikheid is 'n vorm van privaatheid. Vertroulikheid meen dat wanneer ander mense die verslae en artikels oor die studie lees, hulle nie die individue wie aan die studie deelgeneem het kan identifiseer nie. Hulle sal wel sommige van die dinge weet wat die deelnemers gesê het, asook algemene inligting soos deelnemers se oudersom, geslag, en taal. Ek sal probeer om u identiteit privaat te hou deur skuilname te gebruik wanneer ek skryf oor wat u gesê het. As ju sou wou, kan u die naam kies wat u sal wil he ek moet gebruik wanneer ek oor u en u ervaringe skryf.

Die klank opnames en notas van ons onderhoude en vergaderings sal op my rekenaar gestoor word wat slegs toeganklik is deur 'n wagwoord. Ek sal my bes probeer om te verseker dat niemand anderste toegang het tot my geskrewe notas nie deur hulle in 'n lêer te hou. Ek gaan die opnames van ons vergaderings en onderhoude tik sodat ek 'n geskrewe weergawe van dit het. Hierdie geskrewe weergawe van ons onderhoude sal ook op my rekenaar gestoor word en slegs toeganklik wees met 'n wagwoord. Behalwe vir my, sal slegs die tolk wie my assisteer en my studieleier, die inligting verkry uit ons vergaderings, sien en luister. Die rede hiervoor is dat ek hul hulp benodig om die inligting te verstaan en sin te maak van die onderhoude. My studieleier se naam is Leslie Swarts en hy is 'n professor by die Universiteit van Stellenbosch.

As deel van die proses om u ervarings te verstaan, sal ek verskeie kere na die klank opname van on vergaderings luister en die transkripsies lees om sodoende wat ek hoor in temas of groepe in te deel gebaseer op ervarings wat ek voel saam pas. Wanneer ons by die groepsbespreking saamkom, sal ek u van die die temas of te wel groepe vertel en vra wat u daarvan dink, en of u dink ek hulle moet verander.

Sodra ek die tesis vir my Meesters vir die unversiteit geskryf het, sowel as die verslag vir DICAG en u sentrum en die artikels vir joernale sal ander mense van u ervarings kan lees, alhoewel hulle nie u regte naam sal weet nie. Dit is moontlik dat mense van u gemeenskap u kan identifiseer, omdat julle 'n klein gemeenskap is. Om hierby aan te sluit, wanneer ons in groepverband ontmoet sal ek almal vra om nie wat in die groep bespreek word met ander mense buite die groep te deel nie. Indien groepslede nie na die versoek luister nie, is daar die risiko dat u identiteit en ervaringe met ander gedeel kan word. Dit is ongelukkig buite my beheer, maar ek sal my bes probeer om almal aan te moedig om mekaar se identiteit en ervarings vertroulik te hou.

Indien u op enige stadium voel u wil lees wat ek geskryf het, of luister na die opnames van die onderhoude is u welkom om so te maak. Kontak my gerus (Sien Afdeling 8)

## 17. Deelname en onttrekking van deelname

U kan kies of u aan die studie wil deelneem of nie. Indien u vrywillig besluit om aan die studie deel te neem kan u steeds later onttrek sonder enige negatiewe nagevolge. U mag weier om enige vraag te beantwoord wat u nie wil antwoord nie en steeds aan die studie deelneem. U sal steeds U reistoelaag ontvang van R50 as u gedurende die onderhoud besluit u wil onttrek van die studie. Alhoewel hoogs

onwaarskynlik, kan ek u vra om van die navorsingsprojek te onttrek indien ek voel dat dit in u of 'n ander persoon se beste belang is.

### 18. Kontak besonderhede van die navorsers

Indien u enige vrae, of bekommernisse rakende die navorsing het, kontak my, Julia, of my studieleier, Leslie:

- Julia Bingham, die hoof navorsers: 0765692518 or [jrkbingham@gmail.com](mailto:jrkbingham@gmail.com)
- Leslie Swartz, studieleier: 0218083446 or [lswartz@sun.ac.za](mailto:lswartz@sun.ac.za)

### 19. Deelnemers se regte

U kan enige tyd besluit om te onttrek as deelnemer, sonder dat dit u in enige manier benadeel. U deelname aan hierdie studie affekteer geen van U regserkende remedies nie. Indien u enige navrae het rakende u regte wat nie deur Julia of Leslie geantwoord kan word nie, kan u die Afdeling vir Navorsingsontwikkeling aan die Universiteit van Stellenbosch kontak by:

- Ms Maléne Fouché: 021 808 4622 or [mfouche@sun.ac.za](mailto:mfouche@sun.ac.za)

### 20. Handtekening, Toestemming en die ooreenkoms om deel te neem

Indien u besluit dat u aan die studie wil deelneem, sal u die dokument moet teken om te toon dat u bewus is van wat die studie behels en dat u toestemming gee dat die informasie gebruik mag word soos bespreek in die dokument. Ek sal die oorspronklike kopie wat u teken hou en vir u 'n afskrif gee vir toekomstige verwysings.

#### Handtekening van Navorsings deelnemer

Deur die onderstaande te teken, bevestig ek dat die bogenoemde informasie aan my verduidelik is deur Julia Bingham in [*Afrikaans/English/isiXhosa/other*] en dat ek die taal magtig is, of dit is bevredigend aan my vertaal. Julia het my die geleentheid gebied om vrae te stel en die vrae is tot my bevrediging beantwoord.

Ek willig hiermee vrywillig in om deel te neem aan die studie. 'n Afskrif van hierdie vorm is aan my gegee.

\_\_\_\_\_  
**Naam van deelnemer**

\_\_\_\_\_  
**Handtekening van deelnemer**

\_\_\_\_\_  
**Datum**

#### Handtekening van Navorser

Ek, Julia Bingham, verklaar dat ek die inligting in hierdie dokument vervat verduidelik het aan \_\_\_\_\_ [*name van die deelnemer*]. [*Hy/sy*] is aangemoedig en oorgenoeg tyd gegee om

vrae aan my te stel. Dié gesprek is in [*Afrikaans/\*English/\*Xhosa/\*Other*] gevoer en [*geen vertaler is gebruik nie/die gesprek is vertaal in \_\_\_\_\_ deur \_\_\_\_\_*].

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**Handtekening van Navorser**

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**Datum**

## Appendix H

Informed Consent Document: isiXhosa Version



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### IDyunivesiti yaseStellenbosch

#### Isivumelwano sokuthatha inxaxheba kulo mqule wolu phando

*Isiqingatha: isiXhosa*

*Inqununu yolu phando: Julia Bingham, Umphathi: Leslie Swartz*

*Iitoliki zale ncwadi: Nyiko Hlungwani, Zukile Bloro*

*Umvavanyi woshicilelo lokuqala: Tessa Dowling*

#### **Amava wabantu abakhathelela abantwana abakhubazekileyo kwiziphhaluka zaseNtshona Koloni**

❖ *Abakhathaleli* [REDACTED]

Mna Julia Bingham ndithanda ukuba ndikumeme uthabathe inxaxheba kupicotho endilwenzayo. Olu picotho lumalunga namava abantu abathatha inxaxheba ukugcina abantwana abakhubazekileyo, siso ke isizathu endifuna uthabathe inxaxheba. Ndenza ezi zifundo zobuNgcali kwicandelo lePsycholgy kwiDyunivesiti yaseStellenbosch ekulapho ndingumfundi khona.

Ndizama ukuba ndisebenzise zonke iziphumo zolu picotho kwizifundo zam zobuNgcali kwaye endifuna ukuba zipapashwe nanjengoko. Kungumdlala kum ukuba ndibhale inkcazelo emalunga neziko eli (isenta), kwaye ndinike nange-DICAG enikunye nayo. Le nkcazelo iya kuba malunga nezinto esizifumeneyo kucwaningo lwethu malunga namava abantu abakhathalele abo baphila nokukhubazeka kumaziko amathathu akwiNtshona-Koloni. Le nkcazelo iya kubandakanya izigqibo malunga ngenkxaso yabo bakhathalela abantwana abakhubazekileyo kunye namaziko lawo. Le nkcazelo ke isenokusetyenziswa ngabe- DICAG nangala maziko ukukhuthaza nokunika inkxaso. Ngoko ke wonyuliwe njengomthathinxaxheba kolu cwaningo njengoko ukhathalela abantwana abaphila nokukhubazeka kwiziphhaluka ezikwiNtshona-Koloni. Okubalulekileyo, kukuba usebenze kwaye uphumelele kwiintlanganiso kwenye yala maziko alandelayo nakumngxilo omnye neDisabled Children's Activity Group (DICAG): [REDACTED]

Olu xwebhu luya kuba yingcaciso nesikhokelo solu picotho, kwaye sikwaqulathe ngokulindelekileyo komnye nomnye ukuba uyamkela ukuthatha inxaxheba. Ekupheleni kolu xwebhu kukho indawo ekufuneka utyikitye kuyo, ukuba uyamkela kuthabatha inxaxheba. Ngoko ke uya kufumana eyakho ikopi yolu xwebhu ukuze ube nazo zonke iinkcukacha ezingumdlala kuwe xa ufuna ulwazi oluthile.

#### **1. Injongo yolu picotho**

Owona mdlala kolu cwaningo kukufuna ukwazi nokufumana amava njengoko ugcina abantwana abakhubazekileyo eMzantsi Afrika. Kungumdlala kum ukwazi njengoko uzinikele ekukhatheleleni abantwana abakhubazekileyo kweli ziko nasekuhlaleni. Ndifuna ukwazi ukuba imeko yobomi yona ikuphethe njani njengoko ugcina aba bantwana bakhubazekileyo. Oku kunokuba zizinto ezingumqobo (iingxaki), oko kukonelisayo, nezona zinto ezibalulekileyo kulo msebenzi.

Emveni kokuva onke amabali nokuwabhala phantsi ndithemba ukuba abanye abacwaningi abakumaziko ohlukeneyo: elezempilo neminye imibutho bakuthi balufunde olu cwaningo. Ndinethemba lokuba nabanye abantu baya kuyiqonda imeko yokukhathalela nokugcina abantwana abakhubazekileyo kwaye bazi apho banokuxhasa khona kwanangendlela onikeza ngalo uncedo kwaba bantwana. Ndikwathemba ukuba iya kubakhuthaza nabanye ukuba bakuxhase neziko lokugcina abantwana njengoko usenza umsebenzi obalulekileyo wokugcina abakhubazekileyo.

### 1. Emasikulindele komnye nomnye

*Ukuba uyavuma ukuthabatha inxaxheba kwezi zifundo, ndiza kukucela wenze ezi zinto zilandelayo:*

1. Masidibane ngexesha ekulindelekileyo kwiziko elo usebenzela kulo okanye uphumelele kwiintlanganiso zenkxaso yabazali kulo. Ndingathanda ukuba mna nawe sidibane kanye okanye kabini, ukuxoxisana, apho soba sipicotha amava akho okugcina abantwana abakhubazekileyo. Indibano yethu iya kuba lixeshana ekuxhomekeke ziziphi izinto ofuna sabelane ngazo.
2. Emva kweeveki ezimbalwa ndingathanda ukuba sihlngane kwakhona, sidibana nelo qela elikwiziko elo. Kuloo ndibano ndiza kwazisa ngolwazi lwam kumava akho. Ngoko ke nam ndiza kuphulaphula ulwazi lwakho ngoko ndikuthethileyo ukujonga ukuba ndikuqondile konke okuthethiweyo. Kuya kuba lilungelo ke ukuba undixelele nayiphi na into eyoba sisongezelelo. Le ndibano ke iza kuthatha iiyure ezintathu kuphela.
3. Qho xa sihlngana ndiza kuzi-rekoda zonke iintlangano kwaye ndizibhale ukukwazi ukuphinda ndizijonge. Yoba ke lilungelo elivela kuwe ukuba zonke ezi ntlanganiso zirekodwe.
4. Kuzo zonke ezi ntlanganiso umncedisi wam kolu cwaningo uza kuba yinxalenye yalo. Ndiyakwazi ukuthetha isiNgesi kwaye ndiyazi kancinci iAfrikaans kodwa isiXhosa andisazi tu. Umncedisi wam, yena, uyasazi isiXhosa nesiNgesi. Ukuba uyavuma ukuthatha inxaxheba, ndicela uzame ukusebenzisana nomncedisi wam nam ukuze sazane ngcono kolu cwaningo.
5. Oyena ndoqo kwezi zifundo kukwazi amava akho okugcina abantwana abakhubazekileyo. Ngoko ke ukuba uthabatha inxaxheba ndiya kuwamkela amava akho kwaye aya kundinceda ukwazi ngcono ubomi bakho.
6. Ukuba uyavuma ukuthatha inxaxheba ndicela ke undixelele xa ungaqondi kwaye undazise xa ungavumelani noko kuthethiweyo.
7. Ndikulindele ukuba undixelele xa ungenakho ukuwuphendula umbuzo – kulungile!
8. Okubalulekileyo, ndifuna undixelele xa ungaziva ukuba singakwazi ukuqhubeka nentlangano okanye xa ufuna intlangano ime ngezizathu ezithile.

### 1. Imiceli-mngeni nezinye izinto omawuzilindele

Ukuba ke ngoko uyayithabatha inxaxheba kolu cwaningo, ndikucela ukuba sidibane kabini okanye kathathu ngenyanga kwakulo nyaka 2016. Qaphela ukuba zonke iiyure esiya kuzithabatha zoba ntandathu nezo owothi uzithabathe ukuhamba-hamba.

Ndozama ukuba sidibane ngamaxesha angqameneyo ukwenzela ukuba intlanganiso yethu ingabi nakho ukukuphazamisa. Iintlanganiso zethu ndozama ukuba zibe kwindawo apho singenakuphazamiseka khona ukuze uzive ukhululekile xa sithetha. Ndinethemba lokuba umntu oza kutolika uza kwenza uzive ukhululekile ukuthetha ngolwakho ulwimi.

Kule ntlngano sinokuxoxa ngamava nobunzima obufumenyo okanye ngezinto ezikwenza uphelelwe ngumdlu. Ukuba oku kunokwenzeka kuwe undixelele. Singema okomzuzwana okanye siyinqumamise le ntlngano. Ukuba awukulungelanga ukuhlngana nathi, kwaye ufuna ukuthetha nogqirha wengqondo

okanye umcebisi ndingakunceda ndikuxhase kuloo nto. Ungaya eWelgevallen Clinic apha eStellenbosch apho uza kufumana khona uncedo mahala.

- *Ifowuni: 021 808 2696,*
- *Idilesi yokuhlala: Welgevallen Community Psychology Clinic, Welgevallen House, Suidwal Street, Stellenbosch*
- *Imeyili: [WCPC@sun.ac.za](mailto:WCPC@sun.ac.za)*

Ukuba iStellenbosch ikude kuwe ndingakuncedisa ukufumana ugqirha okanye umcebisi okufuphi kuwe. Ndizobhatala ukuyokuma kwishumi loncedo. Fumana iinkcukacha zam kuSection 8.

Kubalulekile kum ukuba ndikuhlonele kwaye ndikukhusele ngexesha sisenza olu cwaningo. Ndazise malunga neembono zakho kwizinto endinokuphucula kuzo.

## 2. Okuya kuba yinzuzo kuwe nakwabanye

Akukho nzuzo ecacileyo ukuba uthabatha inxaxheba kwezi zifundo. Kodwa ikhona inzuzo emandla kwiziqhamo zokuthabatha inxaxheba kwakho:

- ❖ Ndithemba uya kukonwabela ukuthabatha inxaxheba kolu cwaningo.
- ❖ Lithemba kwaye ukuba wanelisekile kwaye uya kuvakalisa nakwabanye amava akho malunga nokukhathalela abantwana abakhubazekileyo kwiziphaluka eMzantsi Afrika.
- ❖ Ndikwathemba ukuba le ngxelo ndiyibhalayo malunga namava akho iya kunceda kwiDICAG nakulaa maziko ukufumana inkxaso.
- ❖ Ndithemba ukuba le nkxaso neyaluphi na uhlobo iya kwenza ngcono ubomi bakho nobosapho lwakho.
- ❖ Le ngxelo ndiyathemba ukuba iya kwazisa oorhulumente namanye amaziko ngentswelo yakho kwaye iya kubakhuthaza ukunika inkxaso emandla kumsebenzi owenzayo.
- ❖ Ndikwathemba ezi zindululo ziya kubanceda nabanye abapicothi abahlukeneyo baqonde ngcono umsebenzi obalulekileyo owenzayo njengomntu okhathalela abantwana abakhubazekileyo kwiziphaluka eMzantsi Afrika.

## 3. Intlawulo yokuthatha inxaxheba

Awuzukufumana ntlawulo ngokuthatha inxaxheba kwezi zifundo. Kwaye qho sihlngana ndiya kukufumbathisa iR50 ukuxhasa kwiindleko zokuhamba. Ndiza kukunika ke ingubo eyoba ngumbulelo, njengoko ndikonwabele ukuthabatha inxaxheba.

## 4. Ukugcina ulwazi lwakho bucala

Yonke ingxelo ehloniphekileyo emalunga nawe ayisayi kunikezwa nakubanina kwaye iya kugcinwa bucala okanye xa ifunwa ngabomthetho. Ingxelo eyimfihlelo ithetha ukuba abo baya kufunda le ngxelo abasayi kwaziswa malunga nabathathi-nxaxheba. Baza kwazi ezinye zezinto ezathethwa ngabantu abathathe inxaxheba qha njengobudala babo, isini okanye ulwimi lwabo. Ezinye iinkcukacha zoba kwimfihlelo. Andisayi kuwabhengeza amagama akho, kwaye amagama ayimfihlo aya kusetyenziswa ngenxa yoko kubhaliweyo. Ukuba uyathanda, ungakhetha igama elingelilo elakho kodwa elingabhekiseleli mntwini xa ndibhala ngawe nangamava akho.

Zonke iingxelo namacwecwe noshicilelo aya kunqatyiswa. Ngoko ziya kugcinwa kwikhompyutha yam apho ubani akasayi kuba namvume yakusebenzisa naninina. Bonke abapicothi, nabo baguquli-lulwimi, baza kuyithatha inxaxheba ekumameleni nasekukhuthazeni kwiingxoxo. Lowo ke indiphetheyo nguLeslie Swartz igama lakhe.

Njengoko ndizama ukwazi awona mava akho, ndakwenje njalo ukuphulaphula ndikulungise oko kuthethwa zizihloko okanye amava amaqela akupicotho olo. Rhoqo sihlngana sakuthetha ngako oku kwaye sakuxoxa nangendlela endinokuphucula ngayo.

Ukuba ndiyabhala upicotho lwam lwedyunivesiti, ingxelo malunga neDICAG, kuza kwenzeka le nto yokuba amanye amaziko nabanye abantu baya kuwafunda amava akho, nangona bengalazi igama lakho eliyinyani. Mhlawumbi abo bakwaziyo baza kwazi ukuba nguwe kule ngxelo ngenxa yokuba uhlala kwindawo encinci kwaye bangakwazi kumava amancinci ukuba ungubani. Xa sihlngana ndakubongoza ukuba akukho uvumelekile ukubhengeza iinkcukacha zawuphi umntu okwiziko lopicotho olo. Ukuba amalungu eqela awamameli le ngecebiso kulindelekile ukuba sibe semngciphekweni wokuba amava akho anganikwa nabanye abantu. Kodwa asingomandla am ndakuzama ukuyigcina iyimfihlelo kwaye ndikhuthaze wonke ubani ukuyigcina kuyimfihlelo esikuthethayo.

Ukuba uyafuna ukuzibandakanya nokufunda oko kubhaliweyo wamkelekile ukukwenza oko. Ndicela uqhagamshelane nam (Icandelo 8).

## **5. Ukuthatha inxaxheba nokurhoxa**

Uya kukhetha ukuba ungathabatha inxaxheba. Ukuba uyazinikela ukuthabatha usenako ukukwazi ukusirhoxisa isigqibo sakho kungekho masolotyachaseneyo. Ungangavumi ukuyiphendula imibuzo kodwa uhlale ulilungu kwezi zifundo. Useza kuzifumana iindleko zokuhamaba eziyiR50 ukuba ugqiba ngexesha lengxoxo ukuyeka. Kulilungelo lakho kwaye elixhomekeke kuwe ukurhoxa, akuxhomekanga komnye umntu.

## **6. Ungadibana njani nabaphandi**

Ukuba uneminye imibuzo malunga nolu picotho, qhagamshelana noJulia okanye uLeslie:

- UJulia Bingham, inqununu yolu phando: 0765692518 okanye [jrkbingham@gmail.com](mailto:jrkbingham@gmail.com)
- ULeslie Swartz, umphathi wam: 0218083446 okanye [lswartz@sun.ac.za](mailto:lswartz@sun.ac.za)

## **7. Amalungelo alowo uthatha inxaxheba**

Unokuzitshintsha izigqibo zakho zokuthabatha inxaxheba nangaliphi na ixesha. Ukuthabatha inxaxheba kwesi sifundo akuchaphazeli amalungelo akho naninina. Ukuba unemibuzo malunga namalungelo akho njengomntu oza kuthabatha inxaxheba kwezi zifundo, koba ukuba uJulia noLeslie abakuniki uncedo, ungaqhagamshelana neDivision for Research Development apha eStellenbosch:

- UMs Maléne Fouché: 021 808 4622 okanye [mfouche@sun.ac.za](mailto:mfouche@sun.ac.za)

## **8. Utyikityo, imvume nesivumelwano sokuthatha inxaxheba**

Ukuba uyavuma ukuthabatha inxaxheba, ungatyikitya ukungqinisisa ukuba uyakuqonda konke malunga nesi sifundo kwaye unikeza imvume yokuba kusetyenziswe iinkcukacha zakho ezibhalwe ngentla. Le kopi iya kugcinwa kwaye woyifumana eyakho.

**Utyikityo lomthathi-nxaxheba wolu phando**

Ngokutyikitya apha ezantsi ndiyangqinisisa ukuba konke okubhalwe ngentla kwacaciswa kum nguJulia Bingham nge[Afrikaans/ngesiNgesi/ngesiXhosa/ngolunye ulwimi] ndakuqonda. Ndalinikwa ithuba lokuba ndiyibuze imibuzo apho ndingaqondi khona.

Ndiyavuma ukuthabatha inxaxheba kwesi sifundo ngokuzithandela. Ndiyifumene ikopi yale fomu.

**Igama lomthathi-nxaxheba**

Utyikityo lomthathi-nxaxheba

uMhla

**Utyikityo loMphandi**

Mna ndinguJulia Bingham ndiyangqinisisa ukuba konke okubhalwe ngentla ndamcacisela kona umthathi-nxaxheba \_\_\_\_\_ [igama lomthathi-nxaxheba] Yena wakhuthazwa kwaye wanikwa ithuba lokundibuza imibuzo . Le ncoko yayiqhuba [ngeAfrikaans/ngesiNgesi/ngesiXhosa/Ezinye] kwaye [wayengekho umntu wokutolika/Le ncoko yatolikelwa esi \_\_\_\_\_ ngu \_\_\_\_\_].

**Utyikityo loMphandi**

uMhla

## Appendix I

## Semi-Structured Interview Schedule: English Version

**Stellenbosch University**

Semi-structured Interview Schedule

*Version: English**PI: Julia Bingham, Supervisor: Leslie Swartz*

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**Caregivers of children with disabilities in semi-rural areas near  
Cape Town, South Africa****I) Individual Experience Questions: Care-centre Participants***A. Everyday life working at the centre*

1. Could you tell me about how you came to work here?
2. Could you tell me why it is that you work here?
3. How many hours per week do you work here?
4. Are you paid for your work here?
5. What is the purpose of this centre?
6. What services do you provide, and for whom?
7. What are your responsibilities at the centre?
8. Could you tell me about a typical day at work?
9. Could you tell me about some more unusual or memorable days at work?

*B. Perspectives of children with disabilities*

10. Can you tell me about the children you care for here?
11. Can you tell me about the disabilities which the children here have?
12. What do you understand about the disabilities?
13. Why do you think the children have the disabilities?
14. Is there anything you do not understand about the disabilities?

*C. Challenges and rewards working at the centre*

15. What, if any, are some of the challenges which you experience here?
16. How do you cope with the challenges you experience?
17. What might help you cope better with these challenges?
18. What, if anything, do you enjoy about working here?
19. What, if anything, do you find rewarding about working here?
20. What might make your work here more rewarding?

*D. Child education, health, and safety*

21. Can you tell me about what it's like to communicate with the children here?
22. Can you tell me what it's like to try to educate the children here?
23. Can you tell me about what it's like when one or more of the children get sick?
24. Can you tell me what it's like to try to keep the children and carers safe here?

*E. Skills, training, and equipment*

25. Do you feel that you have the skills you need to care for the children here?
26. What training, if any, have you had which relates to caring for children with disabilities?
27. Is there any additional training or skills that would help you care for the children here?
28. Do you feel you have the equipment and other supplies which you need to care for the children here?
29. What additional equipment or supplies, if any, would help you in your work here?

*F. Support services at the centre*

30. What support or funding do you have for the centre?
31. Can you tell me about the outside service providers who come here?
32. What, if anything, is the role of DICAG in supporting this centre?
33. How are you supported in the work that you do here?
34. What types of additional support, if any, would help you in your job?
35. What types of additional support, if any, would help the centre as a whole?

*G. Attitudes towards other carers at centre*

36. Can you tell me about the other carers who work here?
37. What is your relationship like with the other carers?
38. What is it like to communicate with the other carers?
39. What is it like to care for the children with the other carers?

*H. Meaning of caring and relationships with children with disabilities*

40. What is your relationship like with the children?
41. What do you think it means to care for children with disabilities?
42. What do you think it means to be caring?
43. How do you feel about caring for children with disabilities?
44. Is there anyone who cares for you? If so, in what ways?

*I. Attitudes towards job*

45. How do you feel about your job?
46. What, if anything, would you like to change about your job?
47. What ideas do you have about possible other jobs in the future?
48. Do you think you will retire?
49. If so, how do you plan to spend your time when you retire?
50. What would you tell somebody who was thinking of working here?
51. If you could do any job in the world, what would it be?
52. If you could spend your free time any way you wanted to, what would you do?

*J. Caring linked to personal health and life in community*

53. What do other people in your community think about the work that you do?
54. How, if at all, does your job here influence other areas of your life? For example,
  - a. Work opportunities
  - b. Relationships
  - c. Family
  - d. Hobbies
  - e. Sleep
  - f. Community involvement
  - g. Other responsibilities
55. How do you spend your time when you are not working at this centre?

56. Can you tell me about your health? For example, your
  - a. Physical health
  - b. Mental health
  - c. Emotional health
  - d. Spiritual health

*K. Additional comments*

57. Is there anything else you'd like to tell me about what it's like for you to care for children with disabilities?
58. Is there anything else you think that other people—like doctors, or people in the government or your community—should know about what it's like for you to care for children with disabilities?
59. How has it felt for you to talk about your experiences with me?
60. Do you have any questions or concerns which you would like to ask me?

## **II) Individual Experience Questions: Parent-centre Participants**

*A. Everyday life with a child with disabilities*

1. Could you tell me about a typical day in your life?
2. Could you tell me about some more unusual or memorable days?
3. Can you tell me what it's like for you to care for a child with disabilities?

*B. Perspectives of children with disabilities*

4. Can you tell me about the disabilities which your child has?
5. What do you understand about your child's disabilities?
6. Why do you think your child has these disabilities?
7. Is there anything which you do not understand about your child's disabilities?

*C. Meaning of caring and relationships with children with disabilities*

8. What do you think it means to care for a child with disabilities?
9. What do you think it means to be caring?
10. How do you feel about caring for your child with disabilities?
11. What is your relationship like with your children, both those with and without disabilities?
12. Can you tell me about what it's like to communicate with your child with disabilities?
13. What would you tell somebody who just found out that their baby has disabilities?
14. What would you tell somebody who was thinking about adopting a child with disabilities?

*D. Reflections of past, present, future: having a child with disabilities*

15. Could you tell me about the first few years when you cared for your child with disabilities?
16. How did you feel during that time?
17. What was difficult about that time?
18. What rewarding about that time?
19. Has anything changed about how you feel caring for your child with disabilities, since that time?
20. Do you have any hopes or fears about your child's future?
21. Do you have any hopes or fears about your own future?

*E. Challenges and rewards of caring for a child with disabilities*

22. What, if any, are some of the challenges which you experience caring for a child with disabilities?
23. How do you cope with the challenges you experience?
24. What types of support, if any, would help you to cope better with these challenges?
25. What, if anything, do you enjoy about caring for a child with disabilities?
26. What, if anything, do you find rewarding about caring for a child with disabilities?
27. What might make caring for your child with disabilities more rewarding?

*F. Skills, training, and equipment*

28. What training, if any, have you had which relates to caring for a child with disabilities?
29. Do you feel that you have the skills you need to care for your child?
30. Is there any additional training or skills that would help you care for your child?
31. Do you feel you have the equipment and other supplies which you need to care for your child?
32. What additional equipment or supplies, if any, would help you care for your child?

*G. Role of Parent-Centre support*

33. Does this centre provide support for you in caring for your child with disabilities?
34. Do you know how this centre is supported or funded?
35. Do any outside services, like health professionals or trainers, visit this centre?

*H. Caring for children with disabilities in a rural community*

36. Who, if anyone, helps you care for your child with disabilities?
37. What is it like to live in your area while caring for a child with disabilities?
38. What is it like to attend social gatherings with your child with disabilities?
39. What is it like to try to educate your child?
40. What is it like to try to keep your child safe?
41. What is it like for you to look after your child when your child is sick?
42. Could you tell me what it's like to travel with your child?
43. What do other people in your community think about your child with disabilities?
44. How, if at all, does your community support you?
45. What, if any, support do you receive from the government or other organisations, to help you care for your child with disabilities?
46. What types of additional support, if any, would help you to care for your child?

*I. Caring linked to personal health and life in community*

47. What is your relationship like with the other people who you live with?
48. Who, if anyone, cares for you, and in what ways?
49. How, if at all, does having a child with disabilities influence other areas of your life? For example,
  - a. Work and job opportunities
  - b. Relationships
  - c. Family
  - d. Hobbies
  - e. Sleep
  - f. Community involvement
  - g. Other responsibilities
50. Can you tell me about your health? For example, your

- a. Physical health
  - b. Mental health
  - c. Emotional health
  - d. Spiritual health
51. How do you spend your time when you are not looking after your child?
52. If you could choose, how would you spend your time?
- a. What would your ideal job be?
  - b. What would your ideal free-time activities be?

*J. Additional comments*

53. Is there anything else you'd like to tell me about what it's like for you to care for a child with disabilities?
54. Is there anything else you think that other people—like doctors, or people in the government or your community—should know about what it's like to care for children with disabilities?
55. How has it felt for you to talk about your experiences with me?
56. Do you have any questions or concerns which you would like to ask me?

**III) Possible probes:**

1. Could you tell me more about that?
2. Could you give me an example of that?
3. Could you tell me a story about that?
4. Could you explain that to me a bit?
5. What do you mean by that?

## Appendix J

## Semi-Structured Interview Schedule: Afrikaans Version

**Universiteit van Stellenbosch**  
**Semi-gestruktureerde Onderhoud Skedule**

Versorgers van kinders met gestremdhede in plattelandse gebiede in die Wes-Kaap  
*Afrikaanse weergawe*  
*HN: Julia Bingham, Studieleier: Leslie Swartz*  
*Vertaler: Anzel Rheeder*

**D) Individuele Ervarings Vrae: Versorgersentrum se pasiënte***A. Alledaagse lewe by die sentrum*

1. Kan u my vertel hoe dit gekom het dat u hier werk?
2. Hoekom werk u hier?
3. Hoeveel ure per week werk u by die sentrum?
4. Word u betaal om hier te werk?
5. Wat is die doel van die sentrum?
6. Watse dienste lewer u en aan wie lewer u die dienste?
7. Wat is u verantwoordelikhede by die sentrum?
8. Hoe verloop 'n normale dag hier by die werk/sentrum?
9. Kan u my vertel van ongewone gebeurtenisse of spesiale dae by die werk wat uitstaan bo die normale dae?

*B. Persepsie van kinders met gestremdhede*

10. Vertel my van die kinders vir wie u sorg hier by die sentrum?
11. Kan u my vertel van die gestremdhede wat die kinders het?
12. Wat dink u is gestremdhede? Hoeveel kennis hetu oor gestremdhede?
13. Hoekom dink u het die kinders die gestremdhede? I
14. Is daar enige iets wat u nie verstaan omtrent die gestremdhede wat die kinders het nie?

*C. Uitdagings en belonings wat gepaard gaan met die werk by die sentrum.*

15. Watse uitdagings ervaar u by die sentrum?
16. Hoe hanteer u (op 'n persoonlike vlak) die uitdagings wat u ervaar.
17. Wat kan u moontlik help om die uitdagings wat u ervaar (op 'n persoonlike vlak) beter te hanteer?
18. Om watse rede, indien daar is, geniet u dit om hier te werk?
19. Wat vind u, indien enigsins, belonend om hier te werk?
20. Wat kan u werk hier by die sentrum moontlik meer belonend maak?

*D. Onderrig, gesondheid en veiligheid van die kind*

21. Kan u my vertel hoe dit is om met die kinders hier te kommunikeer?
22. Kan u my vertel hoe dit is, om die kinders hier iets te probeer leer?
23. Vertel my hoe dit is as een of meer van die kinders siek raak?
24. Kan u my vertel hoe dit is om die kinders asook versorgers se veiligheid te verserker by die sentrum?

*E. Vaardighede, opleiding en toerusting*

25. Voel u dat u die nodige vaardighede besit om na die kinders hier om te sien?
26. Watse opleiding, indien enige, het u wat verband hou met die versorging van kinders met gestremdhede?
27. Is daar enige aanvullende opleiding of vaardighede wat u voel u sal help met die versorging van die kinders hier?
28. Voel u die sentrum het die nodige toerusting en voorraad het, wat u benodig om vir die kinders te sorg?
29. Is daar enige ander toerusting of voorraad wat sal help met die werk wat u doen by die sentrum?

*F. Ondersteunings dienste by die sentrum*

30. Watse ondersteuning of befondsing ontvang die sentrum?
31. Vertel my van die dienste verskaffers wat na die sentrum kom?
32. Wat, indien enige, is die rol wat DICAG speel in die ondersteuning van die sentrum?
33. Hoe word u ge-ondersteun in die werk wat u hier doen?
34. Watse tipe addisionele ondersteuning, indien enige, voel u sal u help met u werk?
35. Watse soort addisionele ondersteuning, indien enige, voel u sal die sentrum as 'n geheel help?

*G. Houding teenoor ander versorgers by die sentrum*

36. Vertel my van die ander versorgers wat hier werk?
37. Hoe is u verhouding met die ander versorgers?
38. Hoe is dit om met die ander versorgers te kommunikeer?
39. Hoe is dit om na die kinders om sien sien, gesamentlik met die ander versorgers?

*H. Versorging en verhoudings met kinders met gestremdhede*

40. Hoe is u verhouding met die kinders?
41. Wat dink u beteken dit om vir kinders met gestremdhede te versorg?
42. Wat dink u behels/beteken dit om iemand te versorg?
43. Hoe voel u daarvoor om vir kinders met gestremdhede te versorg?
44. Is daar enige iemand wat vir u versorg? Indien wel, in watter maniere?

*I. Houding/Gesindheid teenoor werk*

45. Hoe voel u oor u werk?
46. Wat, indien enigesins, sal u wil verander omtrent u werk?
47. Watse idees het u oor moontlike ander beroepskeuses in u toekoms?
48. Dink u, u sal aftree?
49. Indien wel, hoe dink u/waaraan sal u, u tyd spandeer?
50. Wat sal u alles vir iemand sê, wat daaraan dink om hier te kom werk?
51. As u enige werk in die wêreld kon doen, wat sal dit wees?
52. As u enige iets in u vrye tyd kon doen, wat sou u gedoen het?

*J. Versorging met betrekking tot persoonlike gesondheid en lewe in 'n gemeenskap*

53. Wat dink die ander mense in die gemeenskap van die werk wat u doen?
54. Hoe, indien enigsins, beïnvloed u werk ander areas in u lewe? Byvoorbeeld:
  - a. Werks geleentehede
  - b. Verhoudings
  - c. Familie
  - d. Stokperdjies

- e. Slaap
  - f. Betrokkenheid in die gemeenskap
  - g. Ander verantwoordelikhede
55. Wat doen u in u vrye tyd wanneer u nie by die sentrum werk nie?
56. Wat kan u my vertel van u gesondheid? Byvoorbeeld u:
- a. Fisiese gesondheid
  - b. Geestesgesondheid
  - c. Emosionele gesondheid?
  - d. Spirituele gesondheid

*K. Aanvullende kommentaar*

57. Is daar enige iets anderste wat u my graag wil vertel oor hoe dit vir u is om kinders met gestremdhede te versorg?
58. Is daar enige iets anderste wat u dink ander mense- hetsy dit dokters, mense van die regering/owerhede of in u gemeenskap- moet weet oor hoe dit is om na kinders met gestremdhede om te sien/te versorg?
59. Hoe het dit u laat voel om met my te gesels oor u ervaringe?
60. Het u enige vrae of bekommernisse wat u met my wil bespreek?

**II) Individuele Ervaring Vrae: Ouers-Sentrum deelnemers**

*A. Alledaagse lewe met 'n kind met 'n getremdheid*

1. Kan u my vertel van 'n tipiese dag in u lewe?
2. Vertel my van dae met ongewone gebeurtenisse of spesiale geleenthede wat uitstaan bo die normale dae?
3. Kan u my vertel hoe dit vir u is om na 'n kind met gestremdhede om te sien?

*B. Persepsie van kinders met gestremdhede*

4. Vertel my van die gestremdheid wat u kind het?
5. Wat verstaan u alles van u kind se gestremdheid?
6. Hoekom dink u het u kind hierdie gestremdhede?
7. Is daar enige iets wat u nie verstaan rakende u kind se gestremdheid/gestremdhede nie?

*C. Versorging en verhoudings met kinders met gestremdhede*

8. Wat dink u beteken dit om vir 'n kind met gestremdhede te sorg?
9. Wat dink u behels/beteken dit om vir iemand te versorg?
10. Hoe voel u daarvoor om vir u kind wat gestremd is te sorg?
11. Hoe is u verhouding met u kinders met gestremdhede asook die sonder gestremdhede?
12. Kan u my vertel hoe dit is om met u kind wat gestremd is te kan kommunikeer??
13. Wat sal u vir iemand sê wat sopas uitvind hulle baba het gestremdhede?
14. Wat sal u vir iemand sê wat daaraan dink om 'n kind met gestremdhede aan te neem?

*D. Refleksie van die verlede, hede en toekoms: Om 'n kind met gestremdhede te he*

15. Kan u my vertel hoe die eerste paar jaar was, wat u na u kind met gestremdhede moes omsien?
16. Hoe het u gevoel tydens daardie tyd?
17. Wat was moeilik omtrent daardie tyd?
18. Wat was belonend omtrent daardie tyd?
19. Het enige iets verander omtrent hoe u daarvoor voel om vir u kind te versorg vanaf daardie tyd?

20. Het u enige hoop of vrese aangaande u kind se toekoms?

21. Het u enige hoop of vrese aangaande u eie toekoms?

*E. Uitdagings en belonings betrokke by die versorging van 'n kind met gestremdhede*

22. Wat, indien enige, is van die uitdagings wat u ervaar wanneer u na 'n kind met gestremdhede omsien?

23. Hoe hanteer u die uitdagings wat u ervaar?

24. Watse tipe ondersteuning, indien enige, sou u help om die onderskeie uitdagings beter te hanteer?

25. Indien wel, wat geniet u daarvan om na die kinders met gestremdhede om te sien?

26. Indien wel, watse beloning vind u daarin om 'n kind met gestremdhede te versorg?

27. Wat kan moontlik die versorging van u kind met gestremdhede meer belonend maak?

*F. Vaardighede, opleiding en toerusting*

28. Watse opleiding, indien enige, het u al gehad wat verband hou met die versorging van 'n kind met gestremdhede?

29. Voel u dat u die nodige vaardighede het om vir u kind te sorg?

30. Is daar enige addisionele opleiding of vaardighede wat u sal help met die versorging van u kind?

31. Voel u, u het die nodige toerusting en voorraad wat benodig word om 'n kind met gestremdhede te versorg?

32. Watse addisionele toerusting of voorraad sal help/bydrae tot die versorging van u kind?

*G. Rol van ouer-sentrum ondersteuning*

33. Bied hierdie sentrum ondersteuning vir u met die versorging van u kind met gestremdhede?

34. Weet u waarvandaan hierdie sentrum ondersteuning of befondsing ontvang?

35. Besoek enige gesondheidspraktiseerders of opleiers die sentrum?

*H. Versorging van kinders met gestremdhede in plattelandse areas*

36. Wie, indien enigsins, help u om u kind met gestremdhede te versorg?

37. Hoe is dit om in hierdie area te woon met 'n kind met gestremdhede?

38. Hoe is dit om sosiale geleenthede by te woon met u kind met gestremdhede?

39. Hoe is dit om u kind te probeer iets leer?

40. Hoe is dit om u kind met gestremdhede se veiligheid te verseker?

41. Hoe is dit vir u om na u kind om te sien wanneer u kind siek is?

42. Vertel my hoe is dit om met u kind te reis?

43. Wat dink die ander mense in die gemeenskap van u kind met gestremdhede?

44. Hoe, indien enigsins, ondersteun u gemeenskap u?

45. Watse, indien enige, ondersteuning ontvang u van die regering of ander organisasies, wat u help met die versorging van u kind met gestremdhede?

46. Watse addisionele ondersteuning sal bydrae tot/help met die versorging van u kind?

*I. Versorging wat verband hou met persoonlike gesondheid en lewe in die gemeenskap*

47. Hoe is u verhouding met die ander mense saam wie u woon?

48. Wie, indien enige iemand, sorg vir u en op watse manier?

49. Hoe, indien enigsins, word u lewe beïnvloed omdat u 'n kind met gestremdhede het?

Byvoorbeeld:

- a. Werk, Beroepskeuses en Werksgeleenthede

- b. Verhoudings
  - c. Familie
  - d. Stokperdjies
  - e. Slaap
  - f. Betrokkenheid in die gemeenskap
  - g. Ander verantwoordelikhede
50. Vertel my van u gesondheid? Byvoorbeeld, u:
- a. Fisieke gesondheid
  - b. Geestesgesondheid
  - c. Emosionele gesondheid
  - d. Spirituele gesondheid
51. Hoe spandeer u, u vrye tyd, wanneer u nie na u kind omsien nie?
52. As u kon kies, hoe sou u, u tyd wou spandeer?
- a. Wat sal u ideale/droom werk wees?
  - b. Wat sou u ideale vrye-tyd aktiwiteite wees?

*J. Aanvullende kommentaar*

53. Is daar enige iets anderste wat u my wil vertel oor hoe dit vir u is om na 'n kind met gestremdhede om te sien?
54. Dink u daar is enige iets anders wat ande mense – soos dokters, mense in die regering of u gemeenskap- moet weet oor hoe dit is om na 'n kind met gestremdhede om te sien?
55. Hoe het dit u laat voel om met my te gesels oor u ervaringe?
56. Het u enige ander vrae of bekommernisse wat u met my wil bespreek?

**III) Moontlike opvolg vrae:**

- 1. Kan u my meer daarvan vertel?
- 2. Kan u vir my 'n voorbeeld daarvan gee?
- 3. Vertel vir my 'n storie daaroor?
- 4. Kan u dit vir my verduidelik?
- 5. Wat bedoel u daarmee?

## Appendix K

Semi-Structured Interview Schedule: isiXhosa version

IDyunivesiti yaseStellenbosch

**Imibuzo yoDliwanondlebe namalungu [Ungayongeza neminye imibuzo]***Isiqingatha: isiXhosa**Inqununu yolu phando: Julia Bingham, Umphathi: Leslie Swartz**Itoliki yale ncwadi: Nyiko Hlungwani***Amava wabantu abakhathelela abantwana abakhubazekileyo kwiziphaluka zaseNtshona Koloni****I) Imibuzo ngamava ohlukeneyo: Abathathi-nxaxheba kule senta***A. Amava emihla ngemihla abasebenzi kule senta*

1. Ungandixelela ukuba ufikelele njani ukuze uzibone sewusebenza apha?
2. Ungandixelela ukuba kutheni usebenza apha?
3. Usebenza iiyure ezingaphi ngeveki apha?
4. Ingaba uyawubhatalelwa lo msebenzi uwenza apha?
5. Ingaba yintoni injongo yale senta?
6. Wenza omphi umsebenzi? Uwenzela bani?
7. Loluphi uxanduva lwakho apha?
8. Ungandixelela ukuba usuku lwakho emsebenzini lunjani? Wenza ntoni?
9. Ungandichazela ngeemini ezingaqhelekanga zasemsebenzini okanye iimini oya kuhlala uzikhumbula?

*B. Izimvo ngabantwana abakhubazekileyo*

10. Ungandixelela ngabantwana obakhathalelayo apha?
11. Ungandichazela ngeendlela abantwana abalapha abakhubazeke ngazo?
12. Yintoni oyazi ngokhubazeko?
13. Ucinga ukuba kutheni aba bantwana bekhubazekile?
14. Ingaba ikhona into ongayiqondiyo ngokhubazeko?

*C. Imiceli-mngeni nemivuzo yokusebenza apha*

15. Ingaba yeyiphi, ukuba ikhona, imiceli-mngeni othi udibane nayo apha?
16. Unyamezela njani xa uthe wadibana nemiceli-mngeni?
17. Ingaba ziintoni ezingakunceda ukuze ukwazi ukumelana ngcono nale miceli-mngeni?
18. Ingaba ziintoni, ukuba zikhona, ozithandayo ngalo msebenzi?
19. Ingaba ngowuphi umvuzo othi uwufumane kulo msebenzi?
20. Yintoni engawenza lo msebenzi ube nomvuzo ebomini bakho?

*D. Imfundo ngabantwana, impilo nokhuseleko*

21. Ungandichazela ukuba kunjani ukunxibelelana nabantwana abalapha?
22. Ingaba kunjani ukufundisa aba bantwana?
23. Ingaba kunjani xa aba bantwana begula?
24. Ingaba kunjani ukuzama ukugcina abantwana nabakhathaleli balapha bekhuselekile?

*E. Izakhono, ingqeqesho nezixhobo*

25. Ingaba unazo izakhono ezimalunga nokukhathalela abantwana abakhubazekileyo?
26. Ingaba unalo uqeqesho olumalunga nokukhathalela abantwana abakhubazekileyo?
27. Ingaba lukhona olunye uqeqesho onokulufumana olungakunceda ukuze ukhathalele aba bantwana?
28. Ingaba uziva unazo zonke izixhobo nezinye izinto ezifunekayo ezinokunceda kumsebenzi wakho?
29. Ingaba zeziphi ezinye izixhobo ezinokunceda ukuze ukwazi ukwenza umsebenzi wakho kakuhle?

*F. Uncedo lwakule senta*

30. Yeyiphi inkxaso okanye imali eniyifumanayo?
31. Ungandixelela ngabantu bangaphandle abathi baze apha?
32. Ingaba ikhona indlela enixhaswa ngayo yiDICAG?
33. Uxhaswa njani kumsebenzi eniwezayo apha?
34. Zeziphi ezinye iindlela onokuxhaswa ngazo ukuze wenze umsebenzi wakho ngcono?
35. Zeziphi ezinye iindlela eninokuxhaswa ngazo kule senta ukuze nenze umsebenzi wenu ngendlela engcono?

*G. Izimvo kubakhathaleli kule senta*

36. Ungandixelela ngabanye abantu abasebenza apha?
37. Nivana njani nabanye abantu abasebenza apha?
38. Kunjani ukunxibelelana nabanye abasebenzi balapha?
39. Kunjani ukukhathalela abantwana xa usebenza nabanye abakhathaleli balapha?

*H. Intsingiselo yokhathalelo nobudlelwane bokukhathalela abantwana abakhubazekileyo*

40. Bunjani ubudlelwane bakho naba bantwana?
41. Ucinga ukuba ithetha ntoni ukukhathalela abantwana abakhubazekileyo?
42. Ucinga ukuba kuthetha ntoni ukuba nenkathalo?
43. Uziva njani ngokukhathalela abantwana abakhubazekileyo?
44. Ingaba ukhona umntu okukhathaleleyo? Ukuba ukhona, ukukhathalela njani?

*I. Izimvo ngalo msebenzi*

45. Uziva njani ngomsebenzi wakho?
46. Ukuba ikhona, yintoni ongathanda ukuyitshintsha ngomsebenzi wakho?
47. Ingaba ikhona eminye imisebenzi oyijongileyo?
48. Ucinga ukuba uza kudla umhlalaphantsi?
49. Ukuba kunjalo, uza kulitya njani ixesha lakho?
50. Ungathini kumntu onqwenelela ukusebenza apha?
51. Ukuba ungenza nokuba ngowuphi umsebenzi ebomini bakho ingaba ngowuphi?
52. Ukuba unganxesha lokuzonwabela, ungalitya njani elo xesha?

*J. Inkathalelo edityaniswe neyakho impilo emphakathini*

53. Abanye abantu basekuhlaleni bacinga ntoni ngomsebenzi owenzayo?
54. Umsebenzi wakho unoluphi ugalelo kwezinye izinto zobomi bakho? Umzekelo
  - a. Amathuba omsebenzi
  - b. Ezothando
  - c. Usapho
  - d. Izinto othanda ukuzenza
  - e. Ukulala

- f. Unikelo emphakathini
  - g. Olunye uxanduva
55. Wenza ntoni xa ungekho semsebenzini?
56. Ungandichazela ngempilo yakho? Umzekelo
- a. Impilo yomzimba
  - b. Impilo ngokwasengqondweni
  - c. Impilo ngokwasemphefumleni
  - d. Impilo yomoya

*K. Ezinye izimvo*

57. Ingaba ikhona enye into ofuna ukundichazela ngayo malunga nokukhathalela abantwana abakhubazekileyo?
58. Ingaba zikhona ezinye izinto ofuna abanye abantu abafana noogqirha, abantu basekuhlaleni okanye urhulumente, ofuna bayazi ngalo msebenzi?
59. Uzive njani ngokuthetha nam ngomsebenzi wakho?
60. Unayo imibuzo ofuna ukundibuza?

**II) Imibuzo ngamava ohlukeneyo: Ebhekiswe kubazali**

*A. Ubomi bemihla ngemihla nomntwana okhubazekileyo*

1. Ungandichazela ngosuku lwakho? Wenza ntoni yonke imihla?
2. Ungandichazela ngeemini ezingaqhelekanga zasemsebenzini okanye iimini oya kuhlala uzikhumbula?
3. Ingaba kunjani ukukhathalela umntwana okhubazekileyo?

*B. Izimvo ngabantwana abakhubazekileyo*

4. Ungandixelela ntoni ngendlela umntwana wakho akhubazeke ngayo?
5. Uqonda ntoni ngokukhubazeka komntwana wakho?
6. Ucinga ukuba kutheni lo mntwana wakho ekhubazekile?
7. Ingaba ikhona into ongazange wayiqonda ngokukhubazeka kwalo mntwana wakho?

*C. Intsingiselo yokhathalelo nobudlelwane nabantwana abakhubazekileyo*

8. Ucinga ukuba kuthetha ukuthini ukukhathalela umntwana okhubazekileyo?
9. Ucinga ukuba kuthetha ntoni ukuba nenkathalo?
10. Uziva njani ukukhathalela umntwana okhubazekileyo?
11. Bunjani ubudlelwane bakho nabantwana bakho? Abakhubazekileyo nabangakhubazekanga?
12. Kunjani ukunxibelelana nomntwana wakho okhubazekileyo?
13. Ungathini kumntu osanda kufumana umntwana okhubazekileyo?
14. Ungathini kumntu ofuna ukukhulisa umntwana okhubazekileyo?

*D. Amahla-ndinyuka neziphumo zokuba nomntwana okhubazekileyo: kwixesha langoku, kwixesha elizayo nakwixesha elidlulileyo*

15. Ungandichazela ngeminyaka yokuqala owawukhathalela umntwana wakho okhubazekileyo?
16. Waziva njani ngelaa xesha?
17. Yayiyintoni eyayinzima ngelaa xesha?
18. Yayingomphi umvuzo welaa xesha?
19. Ingaba usaziva ngendlela efanayo malunga nokukhathalela umntwana wakho okhubazekileyo? Ikhona into etshintshileyo?

20. Ingaba ikhona iminqweno okanye uloyiko malunga nekamva lomntwana wakho okhubazekileyo?
21. Ingaba unayo iminqweno okanye uloyiko malunga nekamva lakho?

*E. Imiceli-mngeni nemivuzo yokukhathalela umntwana okhubazekileyo*

22. Ingaba yeyiphi imiceli-mngeni othe wadibana nayo xa ukhathalela umntwana wakho okhubazekileyo?
23. Umelana njani nemiceli-mngeni ekuhlaselayo?
24. Ungathanda oluphi uhlobo lwenkxaso ukuze umelane ngcono nale miceli-mngeni?
25. Ingaba yintoni oyithandayo ngokukhathalela umntwana okhubazekileyo?
26. Yeyiphi imivuzo othi uyifumane ngokukhathalela umntwana okhubazekileyo?
27. Yintoni engenza ukukhathalela umntwana wakho okhubazekileyo ibe nomvuzo?

*F. Amava, ingqeqesho nezixhobo*

28. Ingaba unalo uqeqesho olumalunga nokukhathalela abantwana abakhubazekileyo?
29. Ingaba unazo izakhono ezimalunga nokukhathalela abantwana abakhubazekileyo?
30. Ingaba lukhona olunye uqeqesho onokulufumana olungakunceda ukuze ukhathalele umntwana wakho?
31. Ucinga ukuba izixhobo nezinye izinto ezifunekayo onazo zanele ukwenza lo msebenzi wokukhathalela umntwana wakho?
32. Ingaba zeziphi ezinye izixhobo ezinokunceda ukuze ukwazi ukwenza umsebenzi wakho kakuhle?

*G. Uncedo olusuka kwiNkxaso yabazali*

33. Ingaba ikhona inkxaso oyifumanyo kule senta ukuze ukhathalele umntwana wakho?
34. Uyazi ukuba le senta iyayifumana njani na inkxaso yemali okanye nayiphi na inkxaso?
35. Bakhona abantu abasebenza kwezempilo okanye abaqeqeshayo abathi baze apha?

*H. Ukunakekelwa kwabantwana abakhubazekileyo kwiziphaluka*

36. Kukhona umntu okuncedisayo ukukhathalela lo mntwana?
37. Kunjani ukuhlala apho uhlala khona nomntwana okhubazekileyo?
38. Kunjani ukuya kwimibhiyozo unomntwana okhubazekileyo?
39. Kunjani ukuzama ukufundisa umntwana wakho?
40. Kunjani ukuzama ukukhusela umntwana wakho?
41. Kunjani ukuzama ukukhathalela umntwana wakho xa egula?
42. Ungandichazela ukuba kunjani ukuhamba nomntwana wakho?
43. Abantu basekuhlaleni bacinga ntoni ngomntwana wakho okhubazekileyo?
44. Ingaba abantu basekuhlaleni bayakuxhasa? Bakuxhasa njani?
45. Ingaba ikhona inkxaso oyifumanayo kurhulumente okanye eminye imibutho ekunceda ekukhathaleleni umntwana wakho okhubazekileyo?
46. Loluphi uncedo ongathanda ukulufumana ukunceda ukukhathalela umntwana wakho?

*I. Inkathalelo edityaniswe neyakhohlo nobakho ubomi basemphakathini*

47. Bunjani ubudlelwane bakho nabantu ohlala nabo?
48. Ukhona umntu okukhathaleleyo? Ukukhathalela njani?
49. Ukuba nomntwana okhubazekileyo kunogalelo olunjani malunga nezinye izinto zobomi bakho? Umzekelo:

- a. Umsebenzi namathuba omsebenzi
  - b. Ubudlelwane nabanye abantu
  - c. Usapho
  - d. Izinto othanda ukuzenza
  - e. Ukulala
  - f. Unikelo emphakathini
  - g. Olunye uxanduva
50. Ungandichazela ngempilo yakho? Umzekelo
- a. Impilo yomzimba
  - b. Impilo ngokwasengqondweni
  - c. Impilo ngokwasemphefumleni
  - d. Impilo yomoya
51. Ulichitha njani ixesha lakho xa ungajonganga umntwana wakho?
52. Ukuba ungakhetha, ungalicitha njani ixesha lakho?
- a. Ngowuphi owona msebenzi ongawuthanda kakhulu?
  - b. Zeziphi ezona zinto ongathanda ukuzenza xa ungasebenzi?

*J. Ezinye izimvo*

53. Ingaba ikhona enye into ofuna ukundichazela ngayo malunga nokukhathalela abantwana abakhubazekileyo?
54. Ingaba zikhona ezinye izinto ofuna abanye abantu abafana noogqirha, abantu basekuhlaleni okanye urhulumente, ofuna bazazi ngalo msebenzi wokukhathalela abantwana abakhubazekileyo?
55. Uzive njani xa uthetha nam ngobomi bakho?
56. Unayo eminye imibuzo ofuna ukundibuza yona?

**III) Eminyane imibuzo endingayibuza**

1. Yintoni enye onokundixelela ngayo ngaloo nto?
2. Ungandinika umzekelo?
3. Ungandixelela ibali ngaloo nto?
4. Ungandicacisela ngaloo nto?
5. Utsho ukuthini xa usitsho?

## Appendix L

### Description of Checking Processes of Transcriptions and Translations

*The following appendix describes the processes of checking and editing which were involved in the transcription and translation processes of this project:*

#### **isiXhosa Checking**

After receiving the completed isiXhosa transcriptions and translations, I asked a professor in African languages to check one of the translated isiXhosa transcripts. I expected and hoped that the professor would return the document with few edits or criticisms, enabling me to accept the other translated isiXhosa transcripts as likely to be accurate and complete. However, the professor returned the document with extensive additions and edits to both the original isiXhosa transcriptions as well as the English translations of these. The professor said that the editing required was so extensive that it would have been quicker for the audio to be re-transcribed from scratch.

I phoned the interpreter to check what her understanding had been about the instructions for transcribing and translating, and discuss the professor's feedback. The interpreter expressed that she had transcribed and translated in accordance with her understanding of the tasks. She also said that she had sometimes struggled to hear what was said, had made some judgement calls about what to and not to translate, and had also not used a dictionary while translating; rather she aimed to translate the main meaning of what was said, rather than focussing on the exact words or phrasing for translating. Upon her request, I sent her the edited version of the translated transcript from the professor. I expressed that I needed all the other isiXhosa documents to be transcribed and translated with more attention to the detail of what was said and how it was translated, and asked her if she thought it might be better for her or somebody else to do the required revising. (I trusted the interpreter and knew that she had worked hard on the work, and had not intended to produce work that did not meet my standard for it. I had also paid her an hourly rate for the work, rather than a flat rate for getting the job done. Therefore, it was not necessarily a matter of her being the one to revise the work.) We decided it might be better for

somebody else, for example with access to better sound equipment and experience with a more detail-oriented approach to translation to do the revision.

After searching by word of mouth and on the internet, and following up with quite a few contacts, I found a company who offered isiXhosa transcription and translation services, had capacity to do the job within my required time-frame, and was affordable for the project. I sent the company the same instructions for transcription and translation, as well as a short description about the purpose of the project to give some context. The company stated that they always had an independent person check the transcription or translation, before sending it back to the customer. They also charged for the job, not per hour, and specialised in African languages. This seemed like a safe bet for ensuring accurate and complete transcription and translation.

When I received the completed translated isiXhosa transcripts from the company, I excitedly opened the first transcript. I started reading, and noticed that the transcriber had written *unclear* very frequently. I did not recall the audio quality being so poor that this much would have been unclear. While I would not be able to check the isiXhosa speech, I knew I would be able to check the English speech of myself and the interpreter in the audio. I nervously opened the associated audio file, just to check that what I could hear matched what I read in the transcript, and that what was recorded as *unclear* was unclear to my ears too. I started listening, and much to my dismay found that in the first few minutes of audio, I could easily hear the content of chunks of the interpreter's English speech, which had been recorded as *unclear* in the transcript. I phoned the company and spoke to the liaison with whom I had been in touch throughout, and explained my experience of hearing more than I read in the transcript. I added that I had no special soft or hardware that would have enabled me to hear the poor audio quality better.

The liaison asked that I send the transcript and audio file which I had started checking to him, and he would investigate. I used track changes to edit the transcript the first ten minutes of audio, and add what I could hear that was recorded as *unclear* in the transcript. I could only do this with the

English sections, but feared there were likely to be similar cases with the isiXhosa sections. I sent the revised transcript and original audio file to the liaison. After a few days, the company informed me that they discovered that when they had converted the audio files I had sent them, the conversion had lowered the quality of the audio, making it more difficult to make out what was said. The company revised the transcriptions and translations of the documents using the higher quality audio, yielding many additions to the transcripts.

### **Afrikaans Checking**

After receiving Afrikaans transcriptions, I listened to the audio and compared it with the transcriptions. I noticed quite a few discrepancies between the audio and the transcriptions, and so proceeded to edit each one. Many of the discrepancies were words the participants had used that the transcriber identified as a different word. Because I had memories of the interviews with the participants, when I listened to the audio I was able to remember what they had been talking about, and it was easier for me to identify the words they had used, especially if they were somewhat unclear in the audio. I sent the edited Afrikaans transcriptions back to the transcriber, and asked her to proceed with translating the transcriptions. When she was unsure about which English term was the best one to use, she gave options of the terms and highlighted them for me. I then went through the translated transcripts, and chose the words which I felt best fit the participant's language or meaning in that situation, from the options given to me by the translator.

### **English Checking**

When I received the English transcriptions from the postgraduate student who had assisted, I read through the first transcript. I noticed that in the transcript, the interviewer (me) had asked the participant about something she had just said, but the thing which the interviewer was referencing was not recorded in the transcript. I listened to the audio, and found that there was clearly audible speech that had not been transcribed. I phoned the transcriber to check what her understanding had been to the instructions for transcribing, and described what I had found. She assured me that this was not her

usual style, and asked me to please send her the file so that she could edit it. She replied with her edited version and said that she must have been very tired when she transcribed it, because she would usually not have made that many omissions. She assured me that the others had been transcribed better. When I checked the other English files, I immediately found omissions and inaccuracies, indicating a need for thorough editing. I also found an instance when the transcriber had stopped the transcription when the interviewer had thanked the participant near the end of the interview. However, in the audio file, after a few seconds of silence, the participant begins to cry and talks about some difficult experiences in the last few minutes of the interview. The transcriber had not listened to the very end of the audio file, assuming the interview was over. Important data would have been left out completely! I sent all of the English audio files and transcriptions to the transcription company, and asked them to edit the transcriptions. They did so, using track changes, so I was able to see the additions.