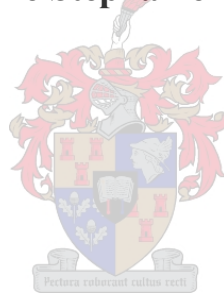

Primary caregivers' perceptions of why their school-aged children with physical disabilities are not attending formal schools in Mabvuku, a high-density location in Harare

by

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Research assignment in partial fulfilment of the requirements for the degree of Masters in Human Rehabilitation Studies (by coursework) at Stellenbosch University

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Declaration

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof, “*Primary caregivers' perceptions of why their school-aged children with physical disabilities are not attending formal schools in Mabvuku, a high-density location in Harare*”, that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

S Kambasha

December 2021

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Abstract

Aim of the study - Children with disabilities face barriers to accessing education and there is a gap in literature reporting the perceptions of caregivers regarding the reasons for these children not getting access to education on par with their age mates. This study aimed to explore and describe the perceptions of primary caregivers of children with physical disabilities residing in Mabvuku, a high-density area in Harare, on why these children are not attending formal school.

Method - This was a descriptive phenomenological study that subjectively explored the perceptions of five mothers of children with disabilities who lived in Mabvuku. Face-to-face in-depth interviews were used for data collection and thematic data analysis was used to analyse the data.

Findings - The findings revealed that financial challenges were the main reason these mothers were not sending their children with disabilities to formal schools. The fact that the schools are physically located far from Mabvuku was also reported as a barrier as travelling with the child to school using public transport posed financial and access challenges. Physical access to the formal schools was also a factor hindering the children from attending school as the infrastructure was not easily accessible to children with disabilities and there is also a limited number of special schools that can accommodate these children. Lastly, the child's disability was also presented as a challenge by the mothers because of the limitations of the impairment and the fact that some were not comfortable leaving their child in the care of someone else, especially with the negative attitudes they experienced from the community.

Conclusion - The study gave an insight into the challenges faced by the mothers which resulted in them not sending their children with disabilities to school. The mothers live with their children with disabilities in poverty. They require support from the government and other relevant stakeholders to improve their circumstances which will impact positively on their children's chances to attend school. Recommendations were made for policy makers and disability practitioners in Zimbabwe.

Abstrak

Doel van die studie - Kinders met gestremdhede het hindernisse vir toegang tot onderwys en daar is 'n leemte in die literatuur wat die persepsie van versorgers rapporteer oor die redes waarom hierdie kinders gewoonlik nie toegang tot onderwys kry op dieselfde vlak as hul ouderdomsmaats nie. Hierdie studie het ten doel gehad om die persepsies van primêre versorgers van kinders met liggaamlike gestremdhede wat in Mabvuku, 'n hoë digtheidsgebied in Harare woon, te ondersoek en te beskryf, en waarom hierdie kinders nie formele skool toe gaan nie.

Metode - Dit was 'n beskrywende fenomenologiese studie wat die persepsie van vyf moeders van kinders met gestremdhede wat in Mabvuku woon, subjektief ondersoek het. Diep-onderhoude van aangesig tot aangesig is gebruik vir die insameling van data en tematiese data-ontleding is gebruik om die data te ontleed.

Bevindinge - Hierdie bevindings het aan die lig gebring dat finansiële uitdagings die hoofrede was waarom hierdie moeders nie hul kinders met gestremdhede na formele skole gestuur het nie. Die feit dat die skole fisies vêr van Mabvuku geleë is, is ook beskou as 'n hindernis omdat die reis met die kind na die skool met openbare vervoer finansiële uitdagings en toegang bied. Fisiese toegang tot die formele skole was ook 'n faktor wat die kinders verhinder om skool toe te gaan, aangesien die infrastruktuur nie maklik toeganklik was vir kinders met gestremdhede nie, en daar ook 'n beperkte aantal spesiale skole is wat hierdie kinders kan akkommodeer. Laastens is die gestremdheid van die kind ook deur die moeders as 'n uitdaging gestel, aangesien hulle nie gemaklik was om hul kind in die sorg van iemand anders te laat nie, veral met die negatiewe houding wat hulle van die gemeenskap ontvang het.

Gevolgtrekking - Die studie het 'n insig gegee oor die uitdagings wat hierdie moeders in die gesig staar, wat daartoe gelei het dat hulle hul kinders met gestremdhede nie skool toe gestuur het nie. Die moeders woon saam met hul kinders met gestremdhede in armoede en benodig ondersteuning van die regering en ander relevante belanghebbendes om hul omstandighede te verbeter wat 'n positiewe uitwerking sal hê op hul kinders se kanse om skool toe te gaan. Aanbevelings is gemaak vir beleidmakers en gestremdes in Zimbabwe.

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To my two pillars of strength, my best friends. No words can explain how much you have helped me through this journey called life. Thank you for always motivating me to aim higher and do better. I have completed this Masters because of your constant love and support.

To the one who created me, my Heavenly Father, I just want to thank you, Lord, for your constant blessings upon me. Thank you for giving me the strength and willpower to start and complete anything I put my mind to doing.

Acronyms

ADL: Activities of Daily Living

CBR: Community Based Rehabilitation

CWD: Children with disabilities

HREC: Health Research Ethics Committee

ICF: International Classification of Functioning, Disability and Health

ILO: International Labour Organization

NGO: Non-Governmental Organizations

PWD: Persons with Disabilities

SDG: Sustainable Development Goals

UNCRPD: United Nations Convention on the Rights of Persons with Disabilities

UNESCO: United Nations Educational, Scientific and Cultural Organization

WHO: World Health Organization

Definition of terms

High-Density Locations: These are areas in cities and towns that are characterised by dense, overcrowded housing where low-income families live who are not able to meet their basic needs (Chirisa, Mutambisi, Chivenge, *et al.*, 2020). In this study, the families interviewed were under privileged and unemployed living below the poverty line.

Inclusive education: UNICEF (2013) defines as educating all children together in the same classroom alongside CWD, which will give them all real learning opportunities and minimize exclusion.

Mainstream/Formal schools: These are structured educational environment that all children without disabilities attend. Children with special educational needs who attend these schools are expected to keep up with the other students in the class with little to no assistance or any special attention.

Perception: This refers to the way in which the individual views, interprets, understands, or regards certain phenomena.

Primary caregivers: In this study this refers to the biological parent/s of the child with a physical disability, or the grandparent/s, aunt or uncle or any other caregiver who is primarily taking care of the child with a physical disability.

Special Education/schools: This refers to form of individualised teaching support that accommodates and addresses the students' individual differences/needs/disabilities. This separates the children based on their impairments or perceived deficits which is in line with the medical model of the disability (Shakespeare, 2018). In this study it was discovered that in Zimbabwe, CWD are being educated in special schools and the available special schools that cater for CWD are run and funded by Non-Governmental Organizations (NGO), churches, private organizations, missionary, and humanitarian organizations as well as the Ministry of Education (Majoko, 2019)

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Chapter 1: Introduction

1.1 Background

The United Nations Flagship Report on Disability and Development emphasises that education is a right for all human beings. It promotes the realisation of the Sustainable Development Goal (SDG) 4, which aims at “ensuring all persons have access to inclusive education and quality life-long learning opportunities” (UN Flagship Report on Disability and Development, 2018:73). Education increases opportunities for employment and life outcomes for children with or without disabilities as shown in a study by Moyo and Manyatera (2014). In the Global South, according to Dziva, Shoko and Zvobgo (2018), children with disabilities (CWD) are denied their fundamental right to education because of barriers such as the environment, personal prejudices, limited qualified teachers, discrimination against persons with disabilities (PWD) and inaccessible mainstream schools. These barriers result in them being socially excluded because they have not acquired the skill and knowledge to be able to participate in the community (UN Flagship Report on Disability and Development, 2018). There is need for low-cost context relevant approaches to enable these children to participate in society and be included in schools, for example Community Based Rehabilitation (CBR).

Community Based Rehabilitation (CBR) is a philosophy adopted in both high income and low to middle income countries and is defined as:

A strategy within general community development for the rehabilitation, poverty reduction, equalization of opportunities and social inclusion of all people with disabilities...through the combined efforts of people with disabilities, their families, organizations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services (International Labour Organization [ILO], United Nations Educational, Scientific and Cultural Organization [UNESCO] and WHO (2004:2).

CBR is introduced into communities using the combined efforts of PWD and their families as well as governmental and non-governmental organizations to improve access to services. The CBR guidelines provide a guide for community practitioners to promote social inclusion of PWD through targeting five components, namely health, education, livelihood, social and

empowerment (WHO, 2010). All the five components need to be targeted to ensure equalisation of opportunities and community participation of PWD. However, the CBR education component in the WHO (2010) report estimated that 90% of CWD in low-income countries do not attend school and an estimated 30% of the world's street children live with disabilities (WHO-CBR, 2010). Implementation of CBR principles has the potential to improve access to education for children with disabilities, especially in low resourced settings like the high-density areas in Zimbabwe.

In September 2013, Zimbabwe signed and ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) which is currently the main international instrument for advancing the human rights of PWD (Dziva et al., 2018). Along with signing the UNCRPD, there are several local policies and legislation that advocate for the inclusion of CWD in regular schools. These include the Zimbabwe Education Act of 1987 as revised in 2006, which aims to “provide for the establishment, maintenance and regulation of Government schools” (Education Amendment Bill, 2005: 3); the Zimbabwe Constitution Amendment Number 20 of 2013 section 75 which states that every Zimbabwean citizen has the right to basic state-funded education (The Constitution of Zimbabwe Amendment No. 20, Act 2013), and the Disabled Persons Act of Zimbabwe of 1996 (Disabled Persons Act *Chapter 17:01*). Some of these policies are outdated as shown by the years in which they came into effect. In 2013, the Constitution of Zimbabwe was updated, and Section 22 was dedicated to PWD which states that, “all institutions and government agencies must recognise the rights of PWD, assist them where possible, give them respect and dignity, develop programs and suitable communications, foster organizations that will help improve their quality of life and ensure all buildings are accessible to PWD” (Constitution of Zimbabwe, 2013:21).

Even though Zimbabwe has signed and ratified the UNCRPD, the country is still not in line with the requirements of Article 24 which states that no PWD shall be excluded from general primary or secondary education because of disability (UNCRPD, 2006). One of the challenges hindering policy implementation is the deepening economic crisis in the country which presents many barriers to families with CWD, especially the low- and middle-income families (The World Bank in Zimbabwe, 2020). There is also not enough political will and effort from the government to improve the lives of PWD in the country (Dziva et al., 2018). Generally, attitudes towards people with disabilities are negative in this country, and such attitudes have been attributed to low prioritisation of disability issues by those in authority responsible for the

formulation and implementation of policies (Dziva et al., 2018). Many communities still believe that disability is a result of witchcraft which can result in stigmatisation and discrimination against children and adults with disabilities and their families (Mandipa & Manyatera, 2014). Masaka (2018) reported that mothers of CWD were socially discriminated against because of their children, for example, some of the fathers of the children left the family when they found out that their children had a disability. Others reported not getting support from their families or communities because of the belief that the CWD is cursed (Masaka, 2018). All these challenges can impact on CWD school attendance.

1.2 Problem statement and rationale

There has been research done on inclusive education and ways to implement it for CWD in Zimbabwe (Siambombe & Isaac, 2019; Chinhara, 2016; Dziva et al., 2018; Sibanda, 2018). Most of this research analysed the policies, the schools, and teachers but there is very little that is known regarding the reasons primary caregivers of these CWD may not send their child to a formal school so as to understand their circumstances from the family's perspective. This limits the policy makers and relevant stakeholders from having a better understanding of the challenges these families face and ways they can be assisted to enable their children to realize their right to education. The insights from the caregivers themselves might help the policy makers and other relevant stakeholders to have a better understanding of the challenges these families face and how they can be assisted to enable their children to realise their right to education. This led to the focus of this study which explored the reasons why primary caregivers with school-aged children with physical disabilities are not attending formal schools in Mabvuku, a high- density location in Harare.

1.3 Motivation and significance

Through ten years of volunteering and working with PWD in various rehabilitation centres in Harare, I observed that almost all the special schools that cater for the educational needs of CWD are in the city centre. The high-density locations do not have any special schools but only mainstream schools (Chinhara, 2016). This made me raise questions about the schooling of CWD living in the high-density areas. I also learnt from the literature that school attendance for CWD is generally poor, especially in low-middle income countries, (UN Flagship Report on Disability and Development, 2018: 76). From a global view, especially in an era where there is more focus on implementation of the SDG-4, there is need to make sure we do not leave

anyone behind through ensuring inclusive and quality education. The Global Education Monitoring Report for 2020, mentions that there is still not enough data or reports on those left behind, the out-of-school population and there are still millions of children who are missing out on their right to education (UNESCO, 2020). So, I wanted to understand from the primary caregivers of these CWD their circumstances impacting on their children's school attendance, be it a mainstream school or a special school. Although the move at a global level is toward inclusive education, in Zimbabwe there is still segregation, whereby most CWD go to special schools. The fact that currently CWD in Zimbabwe are being educated in special schools means CWD in these high-density areas are not accessing any schooling opportunities. Living in these low resourced areas, I sought to understand from the primary caregivers' own perceptions of some of the challenges they face that result in them not sending their children to school. Hearing from the caregivers themselves highlighted areas in which they need support for the CWD to attend school.

1.4 Aim of the study

The main aim of this research is to explore and describe the parents' perceptions of why their school-aged children with disabilities are not attending formal schools in a high-density location in the city of Harare.

1.5 Objectives of the study

The two main objectives of this research were to:

- Describe the primary caregivers' perceptions of the reasons their children are not attending school.

Identify the challenges primary caregivers' face as a result of their children with disabilities not being in school.

1.4 Research question

What are the primary caregivers' perceptions of why their school-aged children with physical disabilities are not attending formal schools in Mabvuku, a high- density location in Harare?

Chapter 2: Literature Review

2.1 Introduction

This chapter presents an overview of literature from previous research related to school attendance of CWD with a particular focus on the Zimbabwean context. The literature review focuses on the following areas: a) Inclusive education b) Education of CWD in Zimbabwe, c) Barriers to school attendance, and d) Caring responsibility and community life for families with CWD.

2.2 Inclusive education

Inclusive education is a system which allows mainstream schools to accommodate children with special learning needs so that they learn alongside other children their age in the classroom without being segregated (Mercinah and Nirmala, 2013). It refers to activities and processes that work toward making education relevant and appropriate for all persons (Stubbs, 2008). This is an important concept because it allows CWD to learn skills that increase their sense of belonging in the community (Mercinah & Nirmala, 2013). It promotes participation of CWD in the school communities and works to eliminate discrimination and barriers to learning for all PWD (Stubbs, 2008). Inclusive education was made official in the Salamanca Statement in 1994 at the ‘World Conference on Special Educational Needs’, where world leaders came to a worldwide consensus on future directions for special needs education. The Salamanca Statement emphasises the need for children to attend schools *in their neighbourhoods* and not to be forced to look for schools elsewhere because of their disability (UNESCO, 1994).

In western countries like Canada and the United States of America, learners with disabilities mostly receive education in regular classrooms in mainstream schools (Ferguson, 2008). This is because the initiative for inclusive education for PWD began in the early 1980s which has given these countries three decades to advance in inclusive and special education, working with the children’s parents, the schoolteachers, and the communities (Ferguson, 2008). Even though inclusive education is being implemented in most schools, there are still some neighbourhoods in these countries where CWD are not receiving education due to the schools already being under-resourced and not able to cope because they are over-crowded (Miles & Singal, 2009).

In African countries, the gap in education for children with disability is wider. There is still a need for a shift in the way CWD are perceived and to re-conceptualize mainstream education so that inclusive education can be implemented in the schools (Williams, 2014). Even in countries where inclusive education policies exist, implementation is still a challenge. Chataika, Mckenzie, Swart and Lyner-Cleophas (2012) reported that in South Africa there are a limited number of teachers with the knowledge and skills for inclusive education, but there has been some progress. They now have guidelines that assist them to respond to the diversity of learners within their inclusive education classrooms. In Zimbabwe, efforts are being made to implement inclusive education but there are still many barriers (Sibanda, 2018).

2.3 Education of children with disabilities in Zimbabwe

The education system in Zimbabwe is run by two ministries, the Ministry of Education which focuses on early childhood, primary and secondary education and then the Ministry of Higher Education which focusses on tertiary education and training. The latter is responsible for training of teachers (Chitiyo & Wheeler, 2004). In Zimbabwe, CWD are being educated in special schools and the available special schools that cater for CWD are run and funded by Non-Governmental Organizations (NGO), churches, private organizations, missionary, and humanitarian organizations as well as the Ministry of Education (Majoko, 2019; Chitiyo & Wheeler, 2004). These schools can be found in and around Harare city centre and urban low-density locations and the school fees are usually higher than the school fees for mainstream schools (Masaka, 2018). In studies done in Zimbabwe by Chinhara (2016); Choruma (2007) & Mugumbate and Nyoni (2013) it is evident that the high-density areas are where one generally finds the low-income families. Most primary school aged CWD in these areas are not accessing their right to education, while many of those who are enrolled in special schools are in boarding facilities, far away from their families, friends, and peers because the schools are far from their homes (Chinhara, 2016).

The United Nations Children's Fund (UNICEF, 2013) reported that there are 600,000 CWD in Zimbabwe and 52% of these children have no access to education because of poverty and structural barriers (UNICEF, 2013). Inclusive education would be ideal, but the teachers often do not have the appropriate training and equipment to accommodate these children (Deluca, Tramontano & Kett, 2014).

There have been efforts from the government to implement inclusive education where the Ministry of Education appointed Special Education Officers (SEO) in each of the country's eight provinces (Majoko, 2013). Their job is to ensure that the children with special needs are catered for in schools in their region. Unfortunately, these SEOs are not trained in teaching and some scholars have argued that the advice they give to the teachers in the schools is not practical and it is irrelevant to the context (Majoko, 2013). It is only recently that universities in Zimbabwe started offering teacher training programmes in Special Education, but it is not mandatory for all teachers to go through this training programme (Chitiyo, Hughes, Chitiyo, Changara, Itimu-Phiri, Haihambo, Taukeni, & Dzenga, 2019).

In an effort to help the families with CWD overcome financial challenges, the government of Zimbabwe implemented funding programmes such as the Basic Education Assistance Module (BEAM) which assists CWD who want to attend school but cannot afford it (Nyikahadzoi, Chikwaiwa & Mtetwa, 2013). These families can apply for BEAM to help them pay for school fees for their child to attend school (Nyikahadzoi et al., 2012). Deluca et al. (2014) explained that this programme is for CWD, orphans and other vulnerable children who have never been to school or have had to drop out because of various financial challenges in paying school fees, examination fees, and other levies. For such assistance, CWD must be assessed by healthcare professionals who then advise which school would be best for the child to attend. Unfortunately, not all of those assessed get the funding. In a survey of 186 parents/caregivers conducted by Deluca et al. (2014), 170 of them knew about the BEAM assistance programme, but only 70 applied for assistance and the other 100 parents/caregivers did not for reasons unknown to the researcher. Further research is needed to gain more understanding of the experiences of families in trying to access this programme and the reasons for not applying.

The exact number of special schools in Zimbabwe is not known. Only about 100 special schools are registered with the Ministry of Education (Ministry of Primary and Secondary Education, 2020). In Harare, there are very few places that can take children with severe disabilities who come from families with limited financial resources (Dambi, Jelsma, & Mlambo, 2015). Therefore, these families are left with the option of sending their CWD to the mainstream schools in their communities which are not fit to accommodate CWD because of the inaccessible school environment and the teachers are not trained to accommodate these children (Chinhara, 2016).

2.4 Barriers to school attendance

The 2018 UN Flagship Report on Disability and Development under SDG4 explains the various barriers faced by PWD when it comes to education, especially in low to middle income countries. In the report, data collected from Cambodia, Maldives, Columbia, Gambia, and Uganda shows an estimated rate of primary school completion for children without a disability in these countries of 73% whereas for CWD it is 56% (UN Flagship Report on Disability and Development, 2018: 76). There are no documented aggregated statistics on attendance and completion of school by children with disabilities in Zimbabwe, but the statistics are likely to be lower given the challenges that the country is currently facing.

Social stigma, environmental barriers, financial hardships and accessing a school that will accommodate a CWD are some of the main reasons for non-attendance (McConnell, Savage, and Breitreuz, 2014). Physical proximity of schools has also been found to impact on CWD's school attendance. For example, research conducted by Dambi et al. (2015) found that parents living in high density locations in Harare raising CWD had challenges in finding the schools that accept these children because the schools are often located on the opposite side of town from where they live. The need for transport to take the CWD to these distant schools can strain the family financially. On the other hand, private schools and church-run mission school are more expensive than government schools and boarding schools (Masaka, 2018). Also, special schools for CWD are more expensive than mainstream schools because CWD in special school have smaller class sizes and the children get individual attention from the specially trained teachers (Masaka, 2018).

In a study conducted in the United States of America by Hanson, Horn, Sandall, Beckman, Morgan, Marquart, Bamwell and Chou (2001), caregivers cited the class size, acceptance of their child by the teacher as well as their peers, cultural beliefs, and the level of the teachers' training, as some of the reasons for not sending their child to school. The results from this study were similar to the study that was done in high-density areas in Harare, which showed that the learning facilities in the mainstream schools are not adequate for CWD because they have poor infrastructure which makes it difficult for them to actively participate in and outside the classroom (Chinhara, 2016). In high-density areas in Harare, the learning facilities in the mainstream schools are not adequate for CWD because they have poor infrastructure which makes it difficult for them to actively participate in and outside the classroom (Chinhara, 2016).

In addition to that, Deluca et al. (2014) reported that teachers did not have the resources, skills, and knowledge to accommodate CWD in their classrooms given the high teacher-pupil ratio (1 teacher to 40 students) in many of the primary schools in Zimbabwe. This leaves no room for the teacher to pay attention to the support needs of CWD in their classrooms (Deluca et al., 2014; Chireshe, 2011:157; Mafa & Chaminuka, 2012:37). Other studies conducted in Zimbabwe cited the families' financial burdens and stigmatization from the community as impacting on CWD's school attendance (Dambi et al., 2015). However, a gap still exists in evidence on perceptions of the family caregivers themselves, especially from low resourced areas.

2.5 Caring responsibility and community life for families with a child with disability

Caring for a CWD comes with many responsibilities which require support from the other members of the family and the community (Masaka, 2018). Without external support, caring for a CWD becomes the caregiver's sole responsibility which will require them to make changes to their personal life plans and social life to take care of their CWD (Al-Kandari & Al-Qashan, 2010; Konrad, 2006; Sato, Araki, Ito & Ishigaki, 2015). The burden of care is heightened when the child is not attending school, which leaves the caregiver with no respite from the care responsibilities (Dambi et al., 2015). Both formal and informal support for the family can be limited, which may result in the CWD being viewed as a burden to the family (Chimedza & Peters, 2000).

The responsibility of caring for children, especially CWD, usually falls on the mother of the child (McHatton, 2007). In some instances, the mothers are left by their husbands or the partners because the fathers do not accept the child with disability (Mukushi, Makhubele & Mabvurira, 2019.). A study conducted in Dzivaresekwa, a high-density location in Zimbabwe, by Mukushi et al. (2019) reported that it is common for father to leave the mother following the birth of a child with disability. Mukushi et al. (2019) also reported that fathers who are present in the child's life are not often seen around the home. They are portrayed as people who are not able to express their feelings and, as a result, they overload themselves with work that is outside the home and do what they can to provide materially for the family (Mukushi et al. 2019).

In Zimbabwe, many CWD are discriminated against from birth because communities believe that disability is a punishment from God, evil spirits, or the ancestors (Mukushi et al., 2019). Cultural myths and stigmas also impact on social participation of people with disabilities in Zimbabwe, including schooling. Hanson et al. (2001) state that there could be reactions such as hostility towards the child and mother, and anxiety and fear from the community which can further affect the individual which then leads to more discrimination and prejudice against them. Linking disability with witchcraft as well as seeing disability as a curse is common in some communities in Zimbabwe, according to Choruma (2017). For example, a child born with a disability can be taken as bringing a bad omen to the family and the blame is usually put on the mother of the child. Social acceptance of a child with a disability is very limited in many communities and some CWD are locked up in the house if the parents cannot take them to a rehabilitation centre (Choruma, 2017).

There are previous studies reporting on how caring for CWD can affect the caregiver over time (Dambi et al., 2015; Palamaro, Munsell, Kilmer, Cook, & Reeve, 2012). Dambi et al (2015) reported that finding and retaining employment can be challenging for the family caregivers because of lack of childcare arrangements and this results in increased financial burdens. They found that this is more evident among families who are already struggling financially. Increased stress levels, anxiety, and depression especially for mothers is a common finding in research and the stress levels are reported to be even higher among mothers of CWD whose children are not able to go to school (Bailey, Golden, Roberts & Ford, 2007). Additionally, the caregivers may suffer from physical pain from assisting their CWD with Activities of Daily Living (ADL) by having to lift and carry them many times throughout the day (Dambi et al., 2015).

Population-based studies comparing mothers of CWD and mothers of children who do not have a disability confirmed the high levels of stress, anxiety, and depression among the former (Bailey et al., 2007; Hadi Motamedi, Seyednour, Noorikhajavi, & Afghah, 2007; Scherer, Verhey & Kuper, 2019). Shin and Nhan (2009) reported that poor education, poverty, and lack of social support are contributory factors to the levels of stress and feeling hopeless about the future of their child experienced by the mothers of children with disabilities. What adds on to the caregivers' stress levels, according to Newacheck and Kim (2005), is the fact that healthcare for a child with disabilities costs more because the child is likely to visit the doctor or hospital more often than a child without disabilities and they often need special medication

and special diets for their general wellbeing. In Zimbabwe, the health system has been affected by the economic challenges in the country and it can no longer provide basic health service (Kidia, 2018). The situation makes life difficult for families with CWD because of the extra financial requirements to accommodate the children's healthcare and basic needs.

The family's financial challenges are exacerbated by the lack of availability of accessible transport for PWD in general in Zimbabwe, which is worse for those living in high-density areas. Chiwanga (2017) reports that bus drivers and minibus drivers deny people using wheelchairs access to their vehicles because they regard strapping the wheelchair to the vehicle a burden. Additionally, most public transport vehicles do not have wheelchair ramps and are not easily accessible for PWD to use.

The caregivers and CWD may face many situations which negatively impact on their participation in their communities. In a study by Kay (2011), mothers of CWD reported that they were being socially rejected because of their children's disability and avoided visiting community centres and other public spaces with their children. Similarly, Runswick-Cole (2010) described how mothers of CWD were isolated from friends and family and the community which resulted in very little support for them. However, not all parents have had negative experiences when it comes to raising CWD. In a study conducted by Wai-Ping, Li-Tsang, Kwai-Sang Yau and Kong Yuen (2001) with parents with CWD in Asia, they shared that they valued the present conditions rather than worried about the future or complained about the past which helped in creating favourable conditions when raising a CWD. Their research also found that the mothers of CWD had a high level of education which resulted in better problem-solving skills and understanding their children's condition and had a positive view on their situation (Wai-Ping Li-Tsang et al., 2001). In Zimbabwe, research on caregivers of CWD' caring responsibility is limited and there is a gap in knowledge of what could improve their circumstances and promote the well-being of their children. Little is known about the perceptions of primary caregivers whose children are not attending schools as to why these children are not in school. This study sought to contribute to covering this gap by exploring and describing the perceptions of caregivers raising children with a physical disability in Mabvuku on why these children are not attending school.

Chapter 3: Methodology and Methods

3.1 Research design

This study used a descriptive phenomenological design which aimed to understand the participants' experiences, perceptions and emotions towards a particular situation or event (Reiners, 2012). This approach was found most appropriate to explore and describe the perceptions of the primary caregivers and understand the reasons behind their actions of not sending their CWD to school. Because I intended to represent the voices of the caregivers without influencing them with my preconceived ideas and assumptions, I found this methodology appropriate because it emphasises bracketing of any preconceived assumptions carried by the researcher (Papp, Markkanen, & von Bonsdorff, 2003). This allows description of the participants' perceptions from their point of view while limiting bias from the researcher (Lopez & Williz, 2004). Through the descriptive phenomenological study design, the researcher seeks to understand the meanings embedded in the participants' statements to uncover common shared experiences which then leads to common themes from the findings (Reiners, 2012). The study used qualitative methods to enable me to get an in-depth understanding of the perceptions of primary caregivers of CWD and generate themes from their narratives.

3.2 Research setting

The study was conducted in Mabvuku which is a high-density area with a population of approximately 150000 people, located 17 kilometres east of Harare, the capital city of Zimbabwe (Parliament of Zimbabwe, 2011). The high-density suburbs are areas in cities and towns that are characterised by dense, overcrowded housing where low-income families live. The schools in these areas have a high student to teacher ratio and the teachers are not able to focus on the children's individual needs (Deluca et al., 2014; Chireshe, 2011:157; Mafa & Chaminuka, 2012:37). Mabvuku has 11 mainstream schools, no special school and one day-care facility in the community that takes children with disabilities and teaches them basic activities of daily living (ADL) skills under the condition that the children can at least walk, communicate, feed, and dress themselves. No services are available for children with more severe impairments since those who have high care needs cannot be accommodated in the facility. The few special schools that exist in Harare are in places far from Mabvuku, the closest being 21km away.

3.3 Research population and participants

The study population was made up of primary caregivers of children with physical disabilities living in Mabvuku, Harare. For them to be included in the study, their CWD had to be aged between six and twelve years old and never been to school before. Only primary caregivers who could speak fluent Shona or English were included in the study.

The participants comprised of a total of five biological mothers of CWD. They were selected using volunteer sampling and snowballing sampling (O'Leary, 2017). These mothers were all unemployed and were taking care of their CWD at home. Three of them were married, and two were single mothers. They all had other children except one who only had her CWD. They spoke fluent Shona with a little bit of English. All the children had physical disabilities as well as additional concomitant conditions. Table 1 presents details of the five participants and their CWD.

Table 1: Participants' profiles and details of their CWD

Participant's pseudonym	Marital status	Are they raising other children?	Child's pseudonym	Child's age	Child's disability/diagnosis	Severity of child's disability
Gladys	Single	No	Gire	6 years old	Severe Cerebral Palsy	Very dependent on the caregiver. Cannot walk, sit, stand, communicate, or perform ADLs
Natasha	Married	Yes	Nashe	6 years old	Hydrocephalus, Spinal Bifida	Very dependent on the caregiver. Cannot walk, communicate clearly, stand on his own, perform most ADLs.

Christine	Married	Yes	Kiri	9 years old	Moderate Cerebral Palsy	Moderately dependent on the caregiver. Can walk but stumbles, can sit, stand perform some ADLs. Cannot communicate clearly.
Kassie	Single	Yes	Kwashe	6 years old	Severe Cerebral Palsy	Very dependent on the caregiver. Cannot sit, walk, communicate, perform ADLs.
Clara	Married	Yes	Cleo	11 years old	Cerebral Palsy & Partial Blindness	Moderately dependent on the caregiver. Can walk, communicate, perform most ADLs

3.4 Participant recruitment strategy

Following ethics approval (HREC approval Number 12980- Appendix E), a leader of a support group for caregivers of children with disabilities was approached to assist with recruitment. She distributed a flyer with information about the study among members of the support group and five members volunteered to participate in the study. All five caregivers were the children's biological mothers.

3.5 Data collection

Semi-structured, in-depth interviews were used to collect data. An interview guide (Appendix C) which was translated to Shona was used to guide the conversations with the participants (Appendix D). The interviews were initially scheduled to take place in April 2020, but the sudden lockdown and social distancing measures necessitated by the Covid-19 pandemic delayed the process and the interviews were conducted in July 2020. Once the lockdown restrictions were less strict the researcher was able to conduct the interviews with all five participants in one day at the community centre in Mabvuku. Because of the Covid 19 pandemic we had to meet at a central location that was convenient for the mothers and all of them lived close to the community centre and they chose to meet me there. Some of the mothers brought their children with them and some of them had to arrange care for their CWD at home. I did take this into consideration, and I did offer to visit the mothers in their homes, but they asked to meet me at the community centre instead. The transcriptions were done after all the interviews were completed and there was no time for reflective transcription between the interviews. All the interviews were conducted at a community centre in Mabvuku. The participants were asked to arrive at different times to avoid crowding. As each of them arrived, they were called to a quiet separate room where the interview was conducted by the researcher in Shona, the first language spoken by the majority of residents of Harare. Follow-up interviews were conducted with four of the five participants at their homes to verify and further clarify some of the issues they shared in the initial interviews. Member checking was not done with the 5th mother as she had gone to the rural areas and got stuck there during the Covid 19 lockdown and only returned to Harare on January 5th which was after I conducted the follow up interviews.

All the interviews lasted an average of 25 minutes. All the interviews were recorded using a voice recorder and permission to record was sought through the informed consent process described in Section 3.7.

3.6 Data analysis

The data collected was transcribed verbatim, translated, and then analysed using the six-steps guide to thematic analysis by Braun & Clarke (2006) which was followed as described below:

- 1) I became familiar with the data collected during verbatim transcription of participants' narratives in Shona and then translating them into English. An independent transcriber who has a BA in English and Communication Skills assisted me with the transcription

and translation and she also checked for consistency. After translation of the data to English, I had to read and reread the transcripts to check for consistency of meaning between the Shona and English versions. At this stage, both the Shona and English transcripts were shared with the supervisor, who is proficient in both languages, to verify accuracy of the translations.

- 2) Once I was certain that the translations were consistent with the participants' narratives, I went on to colour coding the interviews according to common phrases and statements, using the same colour for words, phrases, and statements with similar traits.
- 3) I then grouped the codes into common themes and sub-themes.
- 4) The themes and sub-themes were then reviewed and analysed to see how they fitted into the objectives of the study.
- 5) The final selected themes were reviewed and discussed with the project supervisor before they were finalised. At this stage it came out that some of the themes could be merged into one theme and some of the sub-themes could also be combined.
- 6) Once the project supervisor and I were in agreements, I reported my findings which are presented in Chapter 4.

3.7 Scientific rigour/trustworthiness

Trustworthiness in this descriptive qualitative research was ensured by using Lincoln and Guba's (1985) criteria of credibility, transferability, confirmability, and dependability described below:

Credibility

To ensure credibility, the interviews were conducted and captured consistently by the researcher. The participants volunteered to be part of the study and were not coerced into participating. The details of the study were explained to them in Shona so that they fully understood what the study was about. The interviews were conducted in Shona and the participants responses to the interview questions were transcribed verbatim in Shona first, then translated into English and then further back translated into Shona again to ensure no information was lost in translation. Both the Shona and English transcripts were shared with the supervisor, who is proficient in both languages, to verify the accuracy of the translations. Member checking was done during follow up interviews with the participants to verify some

of the information they gave in the first interviews. Member checking is in line with the principles of the chosen methodology for this research project, descriptive phenomenology (Reiners, 2012). As described earlier, the translations and initial themes were verified by the main supervisor to ensure that the analysis represented the accounts of the participants' narratives and the main supervisor peer reviewed all stages of the study.

Transferability

Transferability means the findings of a research study can be transferred into another setting beyond the boundaries of this particular study. The findings for this research project cannot be transferred given the small-scale nature of the study and the fact that phenomenological qualitative study outcomes focus on the lived experiences of the participant; of which different people cannot have identical lived experiences. However, because I have clearly described the process, I believe the research methodology/strategy of this study can be transferred especially since high-density areas in Harare mostly have similar settings and population demographics. However, even though the outcomes may not be transferable, they can still be used to inform what is happening in similar context but with caution.

Dependability

To ensure dependability, I kept an audit trail of all the original transcripts, data analysis and field notes throughout this research process. All these documents will be available for audit trailing.

Confirmability

For confirmability, I kept a journal of my reflections throughout the research process to document my reflections as a way of bracketing my own preconceived ideas and assumptions (Reiners, 2012; Lopez & Williz, 2004). The interviews were audio recorded to maintain the narratives in their original form without any additions or subtractions from me. I also wrote thick descriptions of the data collection and analysis processes.

3.9 Ethical considerations

The study adhered to the ethical principles of the Helsinki Declaration as per the requirements of Stellenbosch University Health Research Ethics Committee (HREC). The proposal was submitted for ethical clearance before commencement of the study (Approval Number 12980-Appendix E). Due to the Covid-19 pandemic there was need to make amendments to the approved proposal so that the data collection process was in line with the Covid-19 regulations. There was also a need to wait until the regulations were eased off in Zimbabwe, so the interviews were conducted in July 2020.

The participants' hands were sanitized, and they had their temperature checked before each interview began. Both the participants and the researcher wore a face mask throughout the process of data collection and the chairs were placed two metres apart from each other. As per the university regulations, there was an "In Time of Covid-19 Register", to allow the researcher to trace the participants if any of them (or I, the researcher) tested positive to the Covid-19 virus after the interviews. The interviews were all completed in one day to limit exposure and movement during the Covid-19 lockdown. The participants were given a detailed explanation of the purpose of the study and the process of data collection before signing the Consent Form (Appendix A) which had been translated into Shona (Appendix B). They were given a chance to ask questions before commencing the interviews and they were told that participation was voluntary, and they had the right to withdraw from the study at any point without any negative implications on their part. The real names of the participants were not used throughout the study for anonymity and confidentiality purposes and pseudonyms were used as shown in Table 1. However, because the participants belonged to the same support group and were already familiar with each other, anonymity was not ensured among themselves. To prevent them from being identified by other in the community we used inner rooms in the community centre. The participants were told that there were no direct benefits for them participating in the study, but the study findings might inform necessary changes to be suggested to responsible authorities which might impact on the opportunities of CWD in Zimbabwe to attend school. No emotional harm was done as the participants were told they did not have to answer any question they were not comfortable answering, and they had the right to withdraw from the study at any point if the interview made them feel uncomfortable. For those participants who might have felt emotionally distressed while sharing their experiences, a social worker was available for counselling if the participants needed it.

Chapter 4: Research Findings

4.1 Introduction

This chapter presents the findings in the form of themes and sub-themes generated from the data. The findings showed that the reasons these CWD are not in school are multifaceted. The main factors mentioned by the participants which were all interlinked were the children's impairments as well as environmental barriers and contextual reasons. The themes generated from the interviews were: a) Financial challenges, b) Unaffordable and discriminatory transport services, c) Challenges related to the child's disability, d) Physical access to local schools & availability of schools and e) Negative attitudes from the community.

4.2 Financial challenges

The mothers all stated that they are living in poverty which is the main reason that their children could not go to school. Their full-time responsibility of taking care of a child with a disability made it impossible for them to look for formal employment. They did not have any source of stable income besides the money they got from selling a few food items by the side of the road (musika) or doing odd jobs cleaning people's houses where they could take their children with them.

"I have to look for people who need help with small, odd jobs so that I can get a little bit of money so that I can get washing soap to wash her nappies and to get her food that is good for her that won't damage her intestines."

-Gladys

Living under such circumstances, the mothers are unemployed and cannot afford to send their children to the special schools in Harare which they said were too expensive.

"For me, the reason why my child is not going to school is because ... the schools that are nearby that take children with the same condition that Gire has, are too expensive for me. If the fees could.... be affordable, that we can afford to pay because the fees are too expensive so we were asking if they can make the fees affordable because it's not all of us who go to work."

-Gladys

“Things are quite expensive for those who have children with a disability. To find a school you struggle, you get into a financial crisis because everything for them is expensive, eh.”

-Kassie

The other expenses related to the child’s disability, for example, the need for assistive devices were also cited as hindering the children from attending school. One of the mothers explained that her child is partially blind and needed corrective lenses so that she could read but the mother had no money to send her to a specialist and to buy the lenses:

“What causes Cleo to not go to school, it’s money. To start off she is partially blind. I spent almost 5 years trying to get her glasses by Sekuru Kaguvi Street, they were saying she needs glasses. They make a person read to see what kind of lens to give them. Since she cannot read and see the things there it was very difficult. They wrote for us to go see a specialist who handles such cases so that you can what, get glasses. I couldn't get money to go see the specialist, so I just left it like that.”

-Clara

Christine, another mother, explained how her son, Kiri, needed to have corrective surgery for his legs to help him walk properly but they are not able to afford the surgery. She stated both her son’s mobility impairment and lack of money for school fees to go to a special school were co-contributing to him not being able to attend school:

“It's like right now he's supposed to go get surgery on his legs, there is no money, the amount they are asking for. But no that's not the (only) reason why he is not going to school. The reason is there is no money for him to go to school. If the money was there, he will just go like that.”

-Christine

Some of the mothers like Gladys are single parents who are now raising their CWD on their own with no support from the fathers because they deserted the mother of the child before or after the child was born. She explained during her interview:

“I look after her (Gire) because the problem was the father of the child ran away during my pregnancy. So, there was no man, I just lived by myself even now I just live with Gire by ourselves.”

-Gladys

Then there were some mothers who are married, but both husband and wife are unemployed or only the husband is employed:

“He doesn’t go to school, there is no money for school. The father doesn’t work, I don’t work. We just sit, we get help from the little roadside stall we what, we sell to get some food to eat.”

-Christine

4.3 Unaffordable and discriminatory transport services

This theme is closely related to the first theme on financial challenges although the challenges related to transport are worsened by both expensive transport services and negative attitudes of the public transport operators. The families do not own their own cars. If they considered sending their children to the special schools in Harare, some would need to catch more than one bus to get to the school. This is expensive for them because the mothers cannot let their children travel on their own and so they must pay double with each trip which adds more to their already strained finances. The public transport drivers can also be rude and unwilling to accommodate people using wheelchairs.

“Even transport, we are here right, the schools are far away, they should provide transport. Right now, if I want to catch a combi with him, the combi drivers refuse if I have his wheelchair, “you have to pay for the wheelchair, etc!” They want to fill up with as many people as possible so if I then put the wheel-chair they feel like I’m taking up space and they are losing money.”

-Natasha

Some of the mothers had other children who were younger than the one with disability. Without options for childcare, they needed to travel with both the child with disability and his/her siblings which was a huge challenge.

“Even when travelling if you need to travel with him, sometimes you will have another child with you. When it comes to carrying, in public transport, you go into a combi so that he gets a seat, yet you don't have enough money. The combi drivers refuse, and you end up having to sit both of them on your lap. One will be big, the other is smaller, it's very hard.”

-Christine

A few of the mothers suggested that the schools provide transport for the children so that the parents would not have to worry about their children using public transport on their own because they would be picked up and dropped off by the school bus.

“Because the school is far, isn't I told you that XX school, in town that's where the school is. Eh, school fees I can look for it. But transport that's what is expensive. I need for someone to pick him up and bring him back.”

-Christine

4.4 Challenges related to the child's disability

The mothers shared that some of the limitations posed by the impairments that the children had were impacting on the children's possibility to go to school. Some of the children are unable to sit or stand or walk on their own, and some require a constant change of clothes because they soiled themselves or quickly got dirty because they would shuffle on the floor to move around. Because of some of their children's high care needs, caregivers were unable to secure school placements for these children because they felt the care that their children need would not be available at the school.

“I'm actually afraid of that, putting her in the hands of someone else, she could be ruined (abused) because these days people are doing all sorts of things. I'm the one who washes her and pads her up. By herself, she cannot do it. Sometimes she messes herself with the diarrhoea, she messes herself. So, she will need someone, to go with her into the bathroom and give her a bath. So, to give this to someone else it will be a challenge times two.”

-Clara

“Like Gire cannot feed herself. Gire can’t speak many words. Gire can’t walk. She is not able to ...is not strong enough to sit on her own, she’s only learning to sit on her own now. She’s not strong enough to sit alone.”

-Gladys

Some of the children had very low levels of intellectual functioning as highlighted by the mothers’ accounts. The mothers felt that such children would not cope at school even if their chronological age is of primary school going age.

“My child not going to school is because he doesn’t really... I personally think he’s not ready enough to understand. Because the way he responds...”

-Kassie

Natasha, another mother, explained that even though Nashe was using a wheelchair, he was still not able to manoeuvre around on his own and needed someone to push him around. She said that the local mainstream school was not an option for her son because there are stairs to go into the classes and no ramps and the toilets were not accessible to wheelchair users.

“The way the toilets are built it’s not possible for a child who uses a wheelchair. Because the steps are too high, so for him to use his wheelchair.”

-Natasha

Gladys mentioned that there needed to be more community outreach sessions by the Rehabilitation Staff. Her daughter, Gire, has severe case of cerebral palsy and even though she is six years old now she only just learned to sit upright on her own and stand alone. Gladys feels that the community rehabilitation was not enough which was impacting her daughter’s development and resulted in restricted participation.

“For me, it’s correct because sometimes you see that her slow development is maybe because I’m the only parent who is always with her most of the time. I’m the only one who’s doing physio on her. She is not being touched by let’s say an old lady doing exercises or by the doctor who’s handling her or doing exercise who is not me her parent. Maybe that’s some of the reasons why her development is slow.”

-Gladys

Some of the mothers believed that if their children were in schools where they could receive rehabilitation services like speech therapy, some of the challenges posed by their impairments could be ameliorated. Christine believes her child would learn to speak better if he got into a school which offers speech therapy, and his naughty behaviour would change too when he interacted with other children of his age. When asked if the way he currently plays with other children at home would affect him interacting with others if he went to school, Christine responded saying:

“If he goes to school, he will be able to change. Because he will see others, that they don’t do that, and he will be seeing that... that they don’t like it. so, in the end, he will change his behaviour. ... which will help him to fix his personality.”

-Christine

When asked about the way he communicates, if she was concerned her son would not be able to communicate with the teachers or his peers if he went to school, Christine went on to say:

“Most people can’t hear him. But It’s not a challenge because the teachers, some of them understand, the teachers he would be given will understand. Plus, if he goes to school, they said he could get what’s called speech therapy. So that he can do what, speak properly.”

-Christine

4.5 Physical accessibility of schools

The mothers shared that even if they wanted to enrol their CWD into the local mainstream schools, the infrastructure at these schools was not made with PWD in mind and therefore having CWD in this environment could potentially be harmful to the children. One of the mothers explained:

“Because the steps are too high, so for him to use his wheelchair he cannot control it himself even if you teach him how to use the chair he cannot use it because some of the places he can’t get to.”

-Natasha

Some of the special schools where the mothers could consider taking their children as boarders also have environmental barriers that need to be addressed so they can accommodate more children with various forms of disability. Considering this, Clara explained:

“For me what I saw... Because when I looked for a place for her at XX, because she is partially blind, they spoke and said since she is a person who can't really see, where they sleep is on the top, up the stairs at the top. So, she won't have anyone who will help her go up and down, up and down. So, because of that, she didn't get a place there.

-Clara

4.6 Negative attitudes from the community

One of the main issues the mothers kept talking about was the negative attitudes from the community, which indirectly could possibly be impacting their decision not to send their children to the local mainstream schools. Some of the experiences they shared were common like not getting the support they needed from the community as well as their extended family. When it comes to community events, the parents mentioned that their children get segregated and are not given the opportunity to participate in activities with others of their age:

“There are times you see that your child is being segregated because you are in church, you see people choosing those that do not have a disability, while they leave your child.”

-Kassie

“In the community, when they did, let's say something like plays or something that normal children will do, there shouldn't be segregation because this one is disabled. We also want our children to interact, so they get used to each other. Whether they are disabled or not, they should interact with that child, so there isn't segregation within the community or in the family.”

-Natasha

The mothers claimed their children are not being given the opportunity to participate because people think they will not be able to do so because of their disability. This segregation impacts

the child and the mothers negatively and makes it hard for the children to interact with others let alone attend formal school with them. Some of the mothers explained that when they gave birth to their child and found out he/she had a disability; it was their first-time hearing about it and they didn't understand what caused it. Some mothers faced a backlash from their in-laws and family members when they found out their child had a disability. The families believed the child was not their son's and would not accept her in the family:

“When I gave birth to her, she had what is called meningitis. Now that she had meningitis, I went to Harare Hospital, and then the doctor said, “The meningitis was caused by jaundice.” So, after I came home and told the parents, I lived with my mother-in-law and father-in-law. Then they said, “Ah we haven't seen this before, so this means the child is not ours.”

-Clara

Another challenge these families face is landlords who are not understanding of the children's condition and as a result, some families end up in conflict with the landlord or even evicted because of the children's behaviour. Gladys explained her situation during our interview, and she stated:

“So, the other issue is renting a place with a disabled child because you can have a landlord who says they don't want to see your child playing outside. Or if your child cries or makes noise because some children have fits, and others scream at night. You can meet someone who will tell you to hush your child because she is making noise. But they don't understand, and I cannot put my hands over my child's mouth to keep them quiet. It's how they are that makes them behave that way when she does that.”

-Gladys

These narratives about the negative attitudes from the community do not directly show us why their CWD are not attending school but the caregivers constantly commented on this issue which seemed to be suggesting that if the CWD were already getting ostracised at church and in the community. More could happen at school when the caregiver was not there.

Chapter 5: Discussion

The study set out to explore primary caregivers' perceptions of why their CWD are not attending school. The gendered nature of care in Zimbabwe reported by earlier researchers (Mukushi et al., 2019) was apparent as only mothers were available to participate in the study although the inclusion criteria included both male and female caregivers. The mothers' accounts brought to light many challenges that they were facing which were encapsulated by the five themes generated by the data analysis, namely, a) Financial challenges, b) Unaffordable and discriminatory transport services, c) Challenges related to the child's disability, d) Physical access to local schools and availability of schools and e) Negative attitudes from the community. This section discusses the findings and their implications in relation to barriers to school attendance for CWD in Mabvuku.

The findings clearly showed that financial challenges were the main reason these mothers are not sending their CWD to school, either local mainstream schools or special schools for CWD. Everything they needed to do for their children needed money (school fees, treatment, transport, food, etc) but because they live in poverty with no source of stable income, they are not able to meet these basic needs for their children. These findings were not surprising given the economic situation in Zimbabwe where poverty in the country has increased significantly over the years with prices of basic commodities going up constantly (Bonga, 2020). The findings also showed evidence of the well-known relationship between disability and poverty especially common in developing countries like Zimbabwe (Muderedzi, 2006). The mothers all believed they would be able to do more for their families if they could do more odd jobs and earn a living. This would only be possible if the CWD were in school, but as they were not able to afford the school fees to send the CWD to school, they experienced a vicious cycle. The child remains at home, the mother cannot work and earn a living and the cycle of poverty continues. As a start, these mothers mentioned that they would like assistance from NGOs for small projects that they could do at home while they take care of their CWD so as to make money so that they can try send their children to school. This would be a steppingstone for them to earn some income.

In addition to the financial challenges shared by the mothers in the interviews, unaffordable and discriminatory transport services made it difficult for them to send their CWD to special schools. So, even though some of the children had been accepted into these schools, the

mothers were not able to afford school fees plus cost of transport to get their children to the schools. Ndebele (2020) reported that PWD in Zimbabwe are sometimes charged double the bus fare by the bus drivers because of their mobility aids. Thus, it is a challenge for the mothers because it adds more to their already strained finances. The country needs to align with the agenda of the Global Sustainable Development Goals and the International Classification of Functioning, Disability and Health (ICF) by providing disability-accessible transport for PWD in Harare. That way, transport would no longer be an environmental barrier to families like these mothers of CWD in Mabvuku. The ICF recognises that the environment factors such as access to transport can be a factor that influences the experiences and participation of PWD in society (World Health Organization, 2001) and this is what the mothers described in the narratives. The negative attitudes from the bus drivers when they travelled with their CWD made it difficult for them to commute daily with their children to go to school if they had to. So, some of the mothers pointed out that it would be helpful to them if the special schools offered transport services. In that way the CWD would be picked up and dropped off by the school bus in Mabvuku. It would be ideal for such buses to have staff members on them to support the children as they travel since some had multiple impairments.

The challenges posed by the impairments that the children presented also made it difficult for them to enrol in school, according to the mothers. This impacted on both the ability of the children to access some of the school facilities and the mothers' confidence with leaving these children under the care of the professionals at the schools even though the professionals are trained and qualified. They felt that placing their children with multiple disabilities into a mainstream school that offered inclusive education may have a negative impact on the children as there is a high chance that they would be discriminated against and possibly abused by other students and staff members because of their disability. Research by Wissink, Van Vugt, Moonen, Stams, and Hendriks (2014) presented similar findings. Wissink et al. (2014) conducted a narrative review of studies on sexual abuse involving children with intellectual disabilities and found that children with intellectual disabilities are more likely to be sexually abused because they are more vulnerable, or not able to communicate clearly to be able to explain what happened to them. In some instances, the perpetrator emotionally threatens a child, and the child is afraid to speak up against them (Wissink et al., 2014). Although not all the children of the mothers in the current study had low intellectual function, the severity of their disabilities raised the mothers' concerns around vulnerability to abuse. One of the mothers, talked about how sending her son to school would help. The UNICEF Lego-Foundation-

Learning-through-Play 2019 report supports their belief because literature in the report talks about how children learn essential critical skills by engaging with each other mentally, physically, and verbally through playing and interacting with each other (UNICEF, 2019). So, children need that interaction with others their age by going to school. To ensure these CWD get the quality education they need, there needs to be an increase in availability of special schools with smaller classes and more staff within their community could be one solution to reduce the mothers' fears and make them consider taking their CWD to these special schools. In support of this, research done by Cologon (2020) showed that there are some children with multiple disabilities that require special schools that can accommodate the multiple needs of the children as compared to inclusive education in mainstream schools. Specific modifications need to happen within the schools so that the CWD can be supported according to their needs in line with the UNCRPD and its social model underpinnings (UNCRPD, 2006). It is important to recognise that every child has the right to be educated and can be educated regardless of his or her level of impairment if placed in the right facility. It is the responsibility of the authorities to make provisions for such children by either increasing the number of special schools or making the mainstream schools more accessible and accommodating for all children.

Those mothers who were comfortable with the idea of sending their children to school were concerned about physical access to local schools and availability of special schools for CWD. Earlier research has shown that there are not enough special schools to accommodate all the CWD in Zimbabwe, more so in low resourced areas (Chitiyo & Wheeler, 2004). There are less than 50 special schools that cater for CWD in Harare (Ministry of Primary and Secondary Education, 2020). As a result, the mothers had to learn as much as they could from their support group and other mothers with CWD so they could teach their CWD basic skills like ADLs for example. A few of the mothers recommended using the community centre as a place for self-help skills training that will be within the community for their children to attend where specially trained teachers could come in and teach their CWD. CBR programmes may help to facilitate such initiatives.

The CWD must be assessed before being placed in a special school. Unfortunately, there is only one facility that does the school placement assessments for all CWD in Harare (Ingrid, 2015:8) which is far from the area of Mabvuku. At this facility, they diagnose and recommend the school the CWD should attend by working with the schools in consultation with teachers, educational psychologists, occupational therapists, parents, and other stakeholders (Majoko,

2019; Ingrid, 2015:8). Although the assessments are free, according to the mothers interviewed in this study, it remains a challenge for parents from low-income families to access such a service because of the need to travel with their CWD using public transport. There is a dire need to decentralise this service and make it available within local communities. One option would be to implement CBR services which provide both assessments and referrals to appropriate services. Such an approach is supported by Bongo, Dziruni, and Muzenda-Mudavanhu (2018), who found that in Ward 20 in Chipinge having services within the community closer to the families and their children or members with disabilities resulted in families being able to access certain services without having to travel to the city.

Although the mothers who participated in this study seemed to prefer special schools, Mercinah and Nirmala, (2013) argued that being in the same school with their non-disabled siblings gives CWD a sense of belonging and they also get to develop emotionally, physically, academically, and socially. This comprehensive development helps them reach their full potential. Ideally, it would have been convenient for mothers with other children to have both the CWD and his/her sibling at the same school if inclusive education was being implemented. In that way the siblings could look out for each other when they were at school and it would reduce transport costs for the mothers. There has been research done over the years in various countries on the relationship between CWD and their siblings where results showed the siblings went through both difficult and beneficial experiences but they always cared for, supported, and protected their disabled sibling (Meltzer & Kramer, 2016; Barr, McLeod, & Daniel, 2008).

Negative attitudes are part of the environmental factors that can restrict a person's participation in the community according to the ICF framework (World Health Organization, 2001). Even though the mothers did not directly state that the negative attitudes from the community were a reason they were not sending their CWD to the local formal school, this was something each of the mothers reported as a challenge they all faced. Negative attitudes of community members were also a concerning factor in the other themes generated in this study. For example, the taxi drivers charging double the taxi fare and discriminating against these mothers and their CWD shows the level of discrimination there is against disabled people in Harare (Ndebele, 2020). The negative attitudes might also be the reason for the mothers fearing that their CWD may not get the support they need at school. If their CWD were being segregated at community events in front of the mothers, it can only be worse in a school environment where they are not present. This segregation would have a negative effect on the CWD and their participation in

society. The negative behaviours from the community could be a result in a cultural beliefs and stigmatisation of PWD reported by earlier studies in Zimbabwe (Mandipa & Manyatera, 2014; Mukushi et al., 2019). Hence, disability awareness to educate the community and other community-based support initiatives are imperative for CWD in Mabvuku and their families.

All the factors shared by the mothers as impacting on their CWD school attendance have far reaching negative consequences on both the mothers and the CWD. On the one hand, schooling has the potential to increase the CWD independence and confidence to interact with age mates (Stubbs, 2008), which are important life-skills for all young persons to acquire so that they can grow into responsible, autonomous citizen. On the other hand, having the CWD in school would allow the mothers respite from care responsibilities and space to participate in livelihood activities. There are certain behaviours that the children may also learn from interacting with other children at school that the mothers cannot necessarily teach. However, without financial resources which emerged as the main factor impacting on the mothers' ability to send their CWD to school, it would remain difficult if not impossible for these families to send their children to school.

Chapter 6: Conclusion and Recommendations

This chapter presents the conclusions made from the study, the study limitations and some recommendations to the relevant stakeholders.

6.1 Conclusion

This research study has provided an insight into the mothers' perspectives of challenges faced by families in Mabvuku related to their children with disabilities' school attendance. The reasons were all interlinked with financial challenges being the main concern for these families who are living in poverty. Making the schools that are available for CWD affordable and provision of transport to and from these schools would address some of the problems the mothers are facing. Implementing inclusive education would also make a huge difference for these CWD as they would be able to attend the local schools with their siblings and peers which would improve their sense of belonging although some mothers may prefer special schools. The mothers also shed light on the fact that the child's disability is a reason they cannot send him or her to school because they fear their child will be taken advantage of in their absence

and they feel that the level of support needed by the child might not be available at school. This study also raises the need for awareness programmes on disability in the community and more CBR programmes for these families as they are struggling from the lack of support within their community. However, we still have a long way to go as a country to try get our education system in line with the CRPD Article 24 guidelines when it comes to the education of PWD. Further research needs to be done on this topic on a larger scale to present more evidence on the needs of these CWD and their families, so that policy makers can be informed about family support needs and educational needs of CWD like those whose mothers participated in this study.

6.2 Study limitations

The data collection process for this research project was challenging because I was not sure how the high levels of anxiety caused by the Covid-19 pandemic impacted the mothers' confidence and readiness for the interviews. However, I tried my best and observed the Covid-19 protocols and make them feel comfortable. Secondly, this was a very small-scale study with a small sample size, which cannot be used to generalise the circumstances of all families with CWD living in similar settings. However, the findings from this research authentically described the primary caregivers' perceptions in a manner that was true to their experience and they can be used as an initial step to understanding the needs of CWD in Mabvuku regarding school attendance.

6.3 Recommendations

Based on the findings of this study, the following recommendations are made for the government of Zimbabwe and other sectors involved in disability work to improve the living circumstances of families with CWDs and enable the children to go to school:

1. Government

- Providing financial assistance for both the caregivers and the CWDs in the form of care dependency grants and disability grants.
- Updating current policies on disability so that they are in line with the UNCRPD guidelines and implementing the policies.

- Reducing the school fees for special schools to make them affordable for all parents with CWD as this would make a huge difference to them and allow more CWD to attend school and be educated in an environment where the teachers and staff understand their various conditions and special needs.
- Implementing inclusive education in the local schools so that they can be accessible for PWD. This will enable the CWD to attend local schools with the necessary support and not have to travel long distances to attend special schools.
- Decentralising the assessment service that CWD require to be assigned to a special school. It could make it available within local communities. One option would be to implement CBR services which provide both assessments and referrals to appropriate services.

2. Non-Governmental Organizations

- Assist by building self-help skills centres for those children with physical disabilities as well as additional concomitant conditions where they can also receive rehabilitation services.
- Facilitate community awareness and CBR programmes to help educate the community about disability and address negative cultural beliefs and prejudices that exclude the CWD and their families from participating in their community.
- Assist the mothers by creating small-scale income generating projects that will support the caregivers so that they can better provide for their families.

3. Community members

- Community members should be more supportive and accommodating of CWDs and their families so that they can participate and be included in different community spheres like everyone else.
- They should help the families renovate the community centre within Mabvuku so that these mothers can use the facility for rehabilitation or teaching lessons if they source a special education teacher who can teach their CWD.
- As community members with common needs, the mothers need to make more use of peer support groups where they support each other by sharing day-to-day joys and

challenges of raising their CWDs. They can occasionally find professionals who can come and speak to them to guide them in their different areas of need including schooling for their children.

- Although it may not be the best solution, the parents can come together and source a volunteer teacher who can come to the community centre to teach the children. This will help the children to access education opportunities and also to interact with other children in their classes.

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Appendices

Appendix A: Participant information leaflet and consent form

TITLE OF RESEARCH PROJECT:	
Primary caregivers' perceptions of why their school-aged children with physical disabilities are not attending formal schools in a high-density location in the city of Harare, Zimbabwe	
DETAILS OF PRINCIPAL INVESTIGATOR (PI):	
Title, first name, surname:	Ethics reference number:
Miss Kuzivakwashe Stephanie Kambasha	12980
Full postal address:	PI Contact number:
12 Crystal Hope Crescent, Goodhope, Westgate, Harare, Zimbabwe	077 968 4454

We would like to invite you to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are completely satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary**, and you are free to decline to participate. In other words, you may choose to take part, or you may choose not to take part. Nothing bad will come of it if you say no: it will not affect you negatively in any way whatsoever. Refusal to participate will involve no penalty or loss of benefits or reduction in the level of care to which you are otherwise entitled to. You are also free to withdraw from the study at any point, even if you do agree to take part initially.

This study has been approved by the Health Research Ethics Committee at Stellenbosch University. The study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice (2006), the Medical Research Council (MRC) Ethical Guidelines for Research

(2002), and the Department of Health Ethics in Health Research: Principles, Processes and Studies (2015).

What is this research study all about?

The main aim is to explore and describe the primary caregiver's perceptions of why their school-aged children with disabilities are not attending mainstream schools in a high-density location in the city of Harare. The study seeks to give the caregivers a voice by giving them space to share their perceptions with the hope that the findings will inform the responsible stakeholders and hence influence improvements in the area of inclusive education for children with disabilities in the high-density suburbs of Harare. There will be 5 families participating in total who will be interviewed one on one. These interviews will be conducted at the caregiver/family homes or at a location the participant feels comfortable meeting with me. The interview will last about 45 minutes to 1 hour.

Why do we invite you to participate?

You have been invited to participate in this study because as a caregiver of a child with physical disability between the age of 6 and 12 years who is not attending school you fit the study's inclusion criteria.

What will your responsibilities be?

You will be asked to participate in a one-on-one interview with the researcher which will be audio recorded and later transcribed. The interview will last about 45 minutes to an hour. You will be asked questions that seek to understand why you think your child is not in school.

Will you benefit from taking part in this research?

Taking part in the study will not benefit you directly but your contribution will assist in understanding the challenges caregivers face when trying to find a formal school for their CWD. Understanding this can aid in creating the necessary support to overcome these challenges.

Are there any risks involved in your taking part in this research?

There are no risks involved in your taking part in this study. If you feel emotionally distressed by the questions and in need of counselling, you will be referred to a social worker at no cost.

If you do not agree to take part, what alternatives do you have?

Not taking part in this study will not impact you in any negative way or affect any existing relationships you have with organizations. Your participation is completely voluntary

Who will have access to your medical records?

Your child’s medical records or your own are not needed by the researcher. You will also not be identified by your own name in the report that will be written on the study. Participants will be assigned a pseudonym (fake name) that will be used on all documents referring to the participant.

Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study. If the participant chooses another location to meet away from their home, their transport will be covered for each study visit. There will be no costs for the participant.

Is there anything else that you should know or do?

You can phone Kuzivakwashe Stephanie Kambasha at 0779 684 454 if you have any further queries or encounter any problems.

You can phone the Health Research Ethics Committee at 021 938 9677/9819 if there still is something that your study doctor has not explained to you, or if you have a complaint.

Please note that the data collected will be shared with the supervisor in charge of this Project, Dr Callista Kahonde.

You will receive a copy of this information and consent form for you to keep safe.

Declaration by participant

By signing below, I agree to take part in a research study entitled “Primary caregivers' perceptions of why their school-aged children with physical disabilities are not attending formal schools in Harare, Zimbabwe.”

I declare that:

I have read this information and consent form, or it was read to me, and it is written in a language in which I am fluent and with which I am comfortable.

I have had a chance to ask questions and I am satisfied that all my questions have been answered.

I understand that taking part in this study is voluntary, and I have not been pressurised to take part.

I may choose to leave the study at any time and nothing bad will come of it – I will not be penalised or prejudiced in any way.

I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan that we have agreed on.

Signed at (*place*) on (*date*) 2020.

Signature of participant

Signature of witness

Declaration by investigator

I Kuzivakwashe Stephanie Kambasha declare that:

I explained the information in this document in a simple and clear manner to
.....

I encouraged him/her to ask questions and took enough time to answer them.

I am satisfied that he/she completely understands all aspects of the research, as discussed above.

I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) on (*date*) 2020.

.....
Signature of investigator

.....
Signature of witness

Appendix B: Shona participant information leaflet and consent form

(Form rekubvuma kupinda mutsvagurudzo)

TITLE OF RESEARCH PROJECT (TSVAGURUDZO IYI YAKANANGANA NE):	
Primary caregivers' perceptions of why their school-aged children with physical disabilities are not attending formal schools in a high-density location in the city of Harare, Zimbabwe	
Maonero evachengeti kana vabereki kuti sei vana vavo vakaremara, varipazera rekuenda kuchikoro, vasirikuenda kuzvikoro sezvinoita vamwe mumarokesheni emuguta reHarare, Zimbabwe	
DETAILS OF PRINCIPAL INVESTIGATOR (PI): (ZVEMUTSVAGURUDZI)	
ZITA: Kuzivakwashe Stephanie Kambasha	Ethics reference number: 12980
KWAANOGARA: 12 Crystal Hope Crescent, Goodhope, Westgate, Harare, Zimbabwe	PI Contact number: 077 968 4454

Munokokwa kuti muve mumwe weavo vanopinda mutsvagurudzo. Tinokumbira munyatso verenga zvakanyorwa mugwaro rino zvichatsvanangura nezve tsvagurudzo iyi. Munogona kubvunza iye arikutsvagurudza, kana pane zvamusinga nyatso nzwisisa. Zvaka kosha kuti manyatso gutsikana kuti manyatso nzwisisa kuti tsvagurudzo iyi ichadei nekuti imi mungabatsira sei. Zvakare, isarudzo yenyu, hamumanikidzwe, uye munogona zvenyu kuramba kupinda mutsvagurudzo ino. Zvichireva kuti munokwanisa kubvuma kuti hongu ndinoda kana kuti kwete. Hakuna chakaipa chinoitika kwamuri kana mati kwete; hapana kana nechakaipa chingakuwanai. Hapana zve dambudziko pakuti maramba kana zve kutapudzirwa rubatsiro rwamungange manga muchiwana. Zvinobvumidzwa kuzoti handichadi zvangu kubatsira mutsvagurudzo iyi kana musisade chero mambenge mabvuma pekutanga

Chirongwa chetsvagurudzo iyi chaka bvumidzwa **neboka renotsvaga zveutano paStellenbosch University iri ku Capetown, South Africa kunova kwandiri kuita**

zvidzidzo zvangu zviri maerererano nemararamiro evakaremara. Pakutsvagurudza ndichatevedzera mitemo yakarongwa pasirose nezvemaitirwo etsvagurudzo (The study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice (2006), the Medical Research Council (MRC) Ethical Guidelines for Research (2002), and the Department of Health Ethics in Health Research: Principles, Processes and Studies (2015).)

Tsvagurudzo iyi yakanangana nezvei?

Chinangwa chikuru, kuongorora nekutsanangura maonero eavo vanochoengeta vana vakaremara, kuti sei vana ava vasirikupinda muzvikoro zveveruzhinji muma rokesheni muguta reHarare. Tsvagurudzo inopa mukana kuvachengeti kuti vataure nhunha dzavo vaine tariro yekuti izvi zvichabatsira kuonesa chokwadi kune avo vanoona nezvedzidzo. Chishuwo ndechekuti pave neshanduko munyaya yekuti vana vakaremara vepiwewo mukana wekusangana nevamwe muzvikoro zveruzhinji muma rokesheni eHarare. Pachave nemhuri shanu dzichange dzichibvunzurudzwa imwe neimwe panya iyi. Bvunzurudzo ichaitirwa pamba penyu kana kuti pamunga sarudza imi kuti tisangane. Bvunzurudzo iyi ichatora nguva isingadarike 1hour.

Sei ndakoka imi kupinda mutsvagurudzo iyi?

Ndakukokai nekuti semuchengeti we mwana akaremara anemakore aripakati pe matanhatu (6) ne gumi nemaviri (12) asiri kupinda chikoro, munonyatso kwana muzvinangwa zveongororo iyi.

Chii chinotarisirwa kwamuri?

Muchabvunzwa mibvunzo iripamusoro pemusoro wenyaya wetsvagurudzo ino sekutsanangura kwandaita. Iyi inonzi interview. Ndichakumbira kurekodha interview kuti mashoko enyu amunenge Mataura ndigozogona kumayeuka pandinonyora pamusoro petsvagurudzo ino. Interview iyi ichatora pakati pe 45minutes ne 1 hour. Muchabvunzwa mibvunzo inotsvaga kunzwisisa kuti sei mwana wenyu asiri muchikoro.

Mune zvamuchawana here pakubatsira mutsvagurudzo iyi?

Kwete. Hamuna henyu chamunowana imi pachenyu, asi pfungwa nemazano enyu zvichabatsira vamwe vanedambudziko serenyu mukuedza kutsvagira vana vakaremara

nzvimbo dzechikoro. Tarisiro yangu ndeyekuti ruzivo nezvinyorwa zvichabuda mutsvagurudzo ino zvichabatsira kuyedza kuti nyaya iyi igadziriswe

Pangave nenjodzi here mukubvuma kwenyu kubatsira tsvagurutso iyi?

Hapana kana nedambudziko. Kana pane chakushungurudzai pamibvunzo yandinenge ndakubvunzai, ndinozokubatsirai kuwana ve counselling vanga kurukura nemi pasina chamuno bhadhara.

Kana musingadi kubatsira tsvagurudzo iyi, mungagona kuita sei?

Kana mukaregera hapana kana chingaitike kwamuri kana kukanganisa ukama hwenyu nema organisation arikukubatsirai. Hazvimanikidwe kupinda mutsvagurudzo iyi.

Ndiani anokwanisa kuona zvinyorwa zvenyu zvekurapwa?

Zvinyorwa zvekurapwa kwemwana wenyu hazvidiwe nemutsvaguridzi uyu. Zita renyu chairo harishandiswe mutsvagurudzo iyi. Muchapiwa mazita mamwe asiri enyu muzvinyorwa zvese zvichashandiswa mutsvaguridzo iyi kuitira kudzivirira kuti varikupinda mutsvaurudzo vasazivikanwa nevanhu vangaverenga zvichabuda mutsvagurudzo.

Pane mari inobhadharwa here kana munhu abatsira tsvagurudzo iyi?

Kwete, hamusi kubhadharwa kuti mubatsire tsvagurudzo iyi. Kana imi muchida kuti tisangane kumwe kunzvimbo kusiri kumba kwenyu, mutsvaguridzi achakupai mari yekufambisa. Imi hamubhadhare chinhu.

Pane zvimwe here zvamunofanira kuziva?

- Munokwanisa kufonera Kuzivakwashe Stephanie Kambasha pa 0779 684 454 kana mune mumwe mubvunzo kana matambudziko.
- Munikwanisa kufona ku Health Research Ethics Committee pa 021 938 9677/9819 kana mune zvamusina kunzwisisa zvizere kubva kune mutsvaguridzi uye kana muine zvichemo
- Ndinoda kuti muzive kuti zvese zvichabuda mutsvaguridzo iyi zvichapiwa mudzidzisi mukuru we tsvaguridzo iyi anonzi Dr Callista Kahonde.
- Muchawana kopi yebepha iri re rekubvuma kupinda mubvunzurudzo kuti muchengete.

Declaration by participant

Nekusayina pazasi, ini..... ndabvuma kupinda mu tsvagiridzo iyi ye “Maonero evachengeti kana vabereki kuti sei vana vavo vakaremarara, vangadai vachipinda chikoro, vasirikuenda kuzvikoro zvinoita vamwe mumarokesheni emuguta reHarare, Zimbabwe.”

Ndinobvuma kuti:

- Ndaverenga bepha reruzivo ne rekubvuma kupinda mubvunzurudzo, kana kuti reverengwa kwandiri uye rekanyorwa mumutauro wandino nzwisisa nekutaura zvakanaka
- Ndawana mukana wekubvunza mibvunzo zvizere uye ndagutsikana kuti mibvunzo wangu wese wapindurwa zvizere.
- Ndinonzwisisa kuti tsvagiridzo iyi haimanikidwe munhu uye ndabvuma ndega kubatsira mutsvagiridzo iyi.
- Ndinobvumudzwa kuramba kubatsira mutsvagiridzo iyi pandinenge ndafungira uye hapana chakaipa chinoitika kwandiri- Ini handizopihwe chirango kana rusarura munzira ipi neipi
- Ndinogona kunzi ndirege kubatsira mutsvagiridzo iyi isati yapera kana mutsvagiridzi aona kuti zvakandinakira kana kuti handisi kutevera mutemo wetsvagiridzo yataka taurirana

Kusaina ku(nzvimbo) musiwe (*date*)
..... 2020.

.....
Kusaina kwe mubereki

.....
kusaina kwechapupu

Declaration by investigator

I Kuzivakwashe Stephanie Kambasha I declare that:

- I explained the information in this document in a simple and clear manner to
- I encouraged him/her to ask questions and took enough time to answer them.
- I am satisfied that he/she completely understands all aspects of the research, as discussed above.
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) on (*date*) 2020.

.....
Signature of investigator

.....
Signature of witness

Appendix C: English interview guide:

1. Could you please tell me a bit about your daughter/son? What has been your experience in raising a child with disabilities?
2. In your opinion and from your experiences, what are the reasons why your child is not in school?
3. Have you tried to find a suitable school for your child to attend?
4. Do you have other children who are going or have been to school? Can you please share some of the challenges you have faced as a caregiver as you tried looking for a school for your child with a disability as compared to the child's siblings who do not have a disability.
5. What are the challenges you face from having your child at home and not attending school at his/her age?
6. What are your thoughts/opinions regarding education of persons with disabilities in Zimbabwe? Do you think the education system in Zimbabwe caters/accommodates CWD? how so?
7. What are some of the changes you would like to see or recommend to your community and family in terms of inclusion of children with disabilities?
8. What are some of the changes you would like to see or recommend to the Ministry of Education or others involved in the education sector for CWD?

Appendix D: Bvunzurudzo – Shona interview guide:

1. Ndinokumbirawo kuti mudiudze nezve mwanasikana /mwanakomana wenyu? Zvii zvamakasangana nazvo mukumurera ari sezvaari- ndichireva hurema hwaanawo?
 2. Semafungiro enyu uye kubva pane zvamakasangana nazvo, zvii zviri kukonzera kuti mwana wenyu asaenda kuchikoro?
 3. Makamboyedza here kutsvaga chikoro chingatora mwana wenyu uyu kana vamwe vana vakaita saye?
 4. Mune vamwe vana here varikuenda kana kuti vakaenda kuchikoro? Muchitarisa zvamakasangana nazvo mukutsvagira mwana wenyu uyu nzvimbo yechikoro mungaenzanisa sei zvamakasangana nazvo nepamaitsvagira chikoro vamwe vana venyu vasina kuremara?
 5. Ndeapi matambudziko amunosangana nawo mukuswera nemwana wezera rake pamba asingapinde chikoro?
 6. Ndiudzeiwo mafungiro enyu nezvekuenda kuchikoro kwevanhu vakaremara munyika yeZimbabwe? Sekufunga kwenyu, hurongwa hwedzidzo mu Zimbabwe, hunehanya here vana vakaremara? Sei muchifunga kudaro?
 7. Ndezvipi zvamungada kuona zvichiitwa munharaunda yenyu nemumhuri menyu panyaya yekuti vana vakaremara vataridzwe hanya- vakwanisewo kunyatsosangana nevezera ravo nekuita zvinoitwa nevamwe vezera ravo?
 8. Ndezvipi zvamungada kuti dai zvashandurwa/zvaitwa neve Bazi reZvedzidzo (Ministry of Education) nevamwe vanoona nezvedzidzo dzevana vakaremara?
-

Appendix E: Ethical approval letter



UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

Approval Notice

New Application

09/03/2020

Project ID :12980

HREC Reference No: S19/10/246

Project Title: Primary caregivers' perceptions of why their school-aged children with physical disabilities are not attending formal schools in a high-density location in the city of Harare.

Dear Miss Kuzvakwashe Kambasha

We refer to your response to modifications received on 13/12/2019. Please be advised that your submission was reviewed and approved by members of Health Research Ethics Committee via expedited review procedures on 09/03/2020.

Please note the following information about your approved research protocol:

Protocol Approval Date: 09 March 2020

Protocol Expiry Date: 08 March 2021

Please remember to use your Project ID 12980 and Ethics Reference Number S19/10/246 on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC 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.

After Ethical Review

Translation of the informed consent document(s) to the language(s) applicable to your study participants should now be submitted to the HREC.

Please note you can submit your progress report through the online ethics application process, available at: [Links Application Form Direct Link](#) and the application should be submitted to the HREC before the year has expired. Please see [Forms and Instructions](#) on our HREC website (www.sun.ac.za/healthresearchethics) for guidance on how to submit a progress report.

The HREC will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: <https://www.westerncape.gov.za/general-publication/health-research-approval-process>. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: [Forms and Instructions](#) on our HREC website <https://applyethics.sun.ac.za/ProjectView/index/12980>

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Mrs. Melody Shana

Coordinator

HREC1

National Health Research Ethics Council (NHREC) Registration Number: