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# CHAPTER 4

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Fighting the Odds:  
Strategies of Female Caregivers of Disabled Children in Zimbabwe

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#### **4.1 ABSTRACT**

Caregivers of disabled children face numerous challenges in meeting their child's needs. Research on Zimbabwean caregivers of disabled children is limited. Yet the difficult socio-economic, political and institutional context is expected to complicate the caregiving task. This article examines the resources and caring strategies of female caregivers in Mutare, Zimbabwe, using a wellbeing framework. Through a mixed-methods approach, the data reveals that external support is extremely limited, particularly due to stigma and a weak state. Caregivers are mostly self-reliant and their strategies focus on enabling themselves to take care of their child.

## 4.2 INTRODUCTION

Caregivers of disabled children face numerous challenges and a tremendous burden in meeting the needs of their child (Green 2007; Heiman 2002; Landsman 2005; Resch et al. 2010). Many studies show that “due to the additional demand on the parent’s time, energy, finances, emotions and possible feelings of inadequacy” (McConkey et al. 2008: 66), families and especially mothers of disabled children lead significantly stressful lives (Heiman 2002; Raina et al. 2005). Understanding the experiences of caregivers is therefore an important theme in disability and care studies globally, although much less literature from developing countries addresses this (Gona et al. 2011; Hartley et al. 2005; Masasa et al. 2005; McNally and Mannan 2013).

Research on Zimbabwean caregivers of disabled children is also limited, despite the fact that studies indicate a high prevalence of disabled children in Zimbabwe (UN 2010; UNICEF 2013; ZNSA 2012)<sup>1</sup>. Moreover, disabled children belong to the most marginalized and ill-treated groups in Zimbabwean society due to severe stigma (Choruma 2007). Furthermore, Zimbabwe is known as a weak state, experiencing political and economic turmoil (Choruma 2007; Khupe 2010; Peters and Chimedza 2000). Interestingly, Zimbabwe has been on the forefront of disability activism and was ‘one of the most disability accessible countries in Africa’ (Devlieger 1995 cited in; Mpofu and Harley 2002). In terms of disability services, it stood out among its neighbors. However, political and economic mismanagement has led to a lack of basic medical and disability services (SIDA 2014; UN 2010). Such difficult socio-economic, political and institutional contexts will, in all likelihood, aggravate the challenges to care for disabled children.

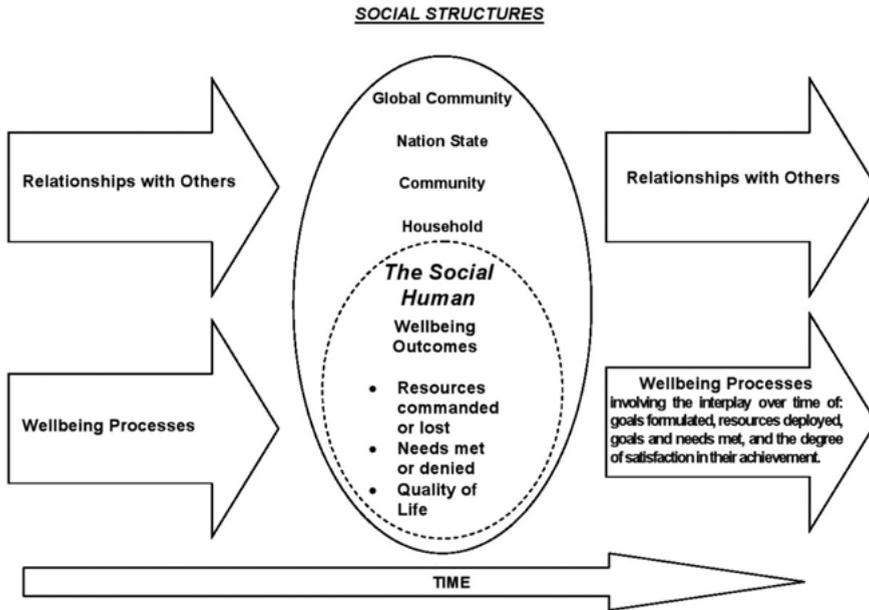
This distinct context of high disability prevalence, stigma, and a weak state warrant a more comprehensive understanding of the experiences of caregivers in Zimbabwe. As studies show that female relatives are the primary caregivers of disabled children (McConkey et al. 2008; Raina et al. 2005), their experiences in particular need emphasis.

In light of the above, this article examines the resources and strategies that Zimbabwean female caregivers employ to realize the wellbeing of their disabled child. Moreover, it discusses how these are shaped by societal structures, specifically the conditions of a weak state and stigma. The study takes a wellbeing approach (McGregor 2006) that has proven successful in examining these concepts in developing countries<sup>2</sup>. Both qualitative and quantitative methods among 61 female caregivers of disabled children in Mutare, Zimbabwe have been used to gain insight into the lives of caregivers and their disabled child. The role of male relatives and other household members is addressed through the social network of female caregivers.

## 4.3 THEORY

### 4.3.1 Wellbeing

This study deploys the wellbeing approach, developed by the Wellbeing in Developing Countries research program at the University of Bath (McGregor 2006). This approach aims to understand poverty by examining people's objective circumstances, their subjective experiences and influential societal structures. Over the past decades, poverty conceptualizations shifted from money-metric approaches such as lack of income or consumption to multidimensional understandings such as the Human Development Index, incorporating levels of income, education and health (Pouw and Gilmore 2012). The Human Development Index in turn was inspired by the basic needs index of Peter Townsend and Amartya Sen's capabilities approach (1999). The latter fostered a multifaceted and wide definition of poverty through focusing on people's freedoms and the opportunities to live a life people have reason to value (Sen 1999). This rather abstract understanding of poverty paved the way to the more applied wellbeing approach to understand "the social and cultural construction of wellbeing in developing countries" (Gough and McGregor 2007: 316). Wellbeing is understood as the result of the interplay between: the resources that a person is able to command; the needs and goals they are able to fulfill with those resources; and the meaning they give to the goals they achieve and the processes in which they engage (Pouw and Gilmore 2012). These components are shaped by society and social collectivity (McGregor 2006). Figure 4 shows the wellbeing framework.



**Figure 4.** A wellbeing framework. Source: McGregor (2006: 25).

The wellbeing methodology comprises three research categories; wellbeing outcomes, wellbeing processes, and wellbeing structures. Wellbeing outcomes consist of resources commanded and lost, needs met and denied, and quality of life achieved. Wellbeing processes and structures influence the wellbeing outcomes and vice versa. The first embody formulating goals and employing strategies to reach these goals. People develop strategies based on resource availability, yet strategies may also produce resources that help in reaching formulated goals. Hence multiple relations exist between resources and strategies. Wellbeing structures reflect the relationships in which human beings are engaged, “across a range of different levels of social structure, and over time” (McGregor 2006: 26). Societal structures exist at the household, community, state and global levels (McGregor 2006). Our focus here is on household, community and state level, and in particular the effect of a weak state and stigma.

#### **4.3.2 Disability and Wellbeing Outcomes and Processes**

The wellbeing approach is designed to measure poverty in developing countries but also bears relevance in a disability context because disability and poverty are interrelated (Choruma 2007; Loeb et al. 2008; Meyer and Mok 2013; Mitra et al. 2013). Malnutrition, for example, can cause disability, and reduced access to resources resulting from disability can aggravate poverty. Therefore, the wellbeing framework

enables an understanding of how caregivers operate to ensure their disabled child's wellbeing in the context of a developing country.

An extensive body of general disability literature, both from developed and developing countries, discusses needs, resources and strategies, but in this article the focus specifically lies on literature about caregivers and their disabled children; that is, disability and care literature.

### *Needs and resources*

The wellbeing approach distinguishes human, social, financial, material and natural needs and resources (McGregor 2006)<sup>3</sup>. In disability and care literature generally, four human needs and resources are considered relevant: physical assistance, medical treatment, education, and information and services (Barratt and Penn 2009; Gona et al. 2011; Heiman 2002; Masasa et al. 2005; McNally and Mannan 2013; Qayyum et al. 2013; Resch et al. 2010; Shapiro and Tittle 1990). Governmental and non-governmental organizations are key in providing these. However, the availability and quality of their contribution is shaped by the condition of the state, existing disability policies and levels of poverty (Marongwe and Mate 2007; Murphy 2010).

Socially, friends, family and community relationships are important. Moreover, social networks, including family and other household members, provide emotional, financial and practical support, especially where institutional facilities are absent (Oh and Lee 2009; Portes 1998). Yet the relations between social networks on the one hand and poverty, fragile states and disability on the other are complex and context specific (Foley and Chowdhury 2007; Isaac et al. 2010; Loeb 2009; O'Brien et al. 1997), and social support may flourish or suffer because of contextual specificities (Gona et al. 2011; Masasa et al. 2005; Milliken and Krause 2002).

Finances cause stress in the lives of disabled children and caregivers because of the high costs of care and the constrained income generation opportunities due to high caring requirements (Heiman 2002; Mitra et al. 2013). In some contexts, the government provides income or subsidies; in others, caregivers often rely on other strategies (Barratt and Penn 2009; Gona et al. 2011; Kaplan 2010).

In addition to basic needs including housing, food, clothes, and sanitation (Allison and Ellis 2001; Beall and Kanji 1999), material needs and resources are transport and assistive devices. Again, the availability and quality of these resources depend on the context. Formal governmental and non-governmental institutions may act as a

supplier, yet in many developing countries this is not self-evident (Marongwe and Mate 2007; Munsaka and Charnley 2013).

Finally, disability and care literature hardly discusses the role of natural needs and resources such as available land or property for income generation. However, the importance of such resources is emphasized in general disability literature, and in wellbeing and livelihood studies focusing on developing countries (Choruma 2007; Verrest 2013).

### *Strategies*

Through various contexts, the needs of disabled children and their caregivers show similarities but available resources differ widely. As such, the strategies that caregivers deploy are also expected to be context specific. Much disability and care literature shows that seeking support from governmental and non-governmental institutions to fulfill human, material and financial needs is a key strategy (McConkey et al. 2008; Raina et al. 2005; Shapiro and Tittle 1990). Others, however, emphasize that formal support institutions are often absent in disadvantaged regions (Loeb 2009; Qayyum et al. 2013), forcing caregivers to develop alternatives. Next, caregivers seek various types of support from social networks; however, as mentioned before, this strategy's viability is context specific (Choruma 2007; Munsaka and Charnley 2013). Furthermore, disability and care literature acknowledges acceptance of the disability as a strategy supporting caregivers in dealing with their task (Green 2007; Hartley et al. 2005; Heiman 2002; Wang et al. 2011). The final strategy is learning skills by the caregiver to adapt to the child's disability, such as giving physiotherapy (Barratt and Penn 2009; Gona et al. 2011).

### **4.3.3 Disability and Wellbeing Structures**

The social, political, economic and institutional contexts affect the caregiving task. Our main concern is with two Zimbabwe specificities that we expect to shape caregiving: stigma and the weak state.

### *Stigma*

In this study we define a stigmatized person as possessing an "attribute that is deeply discrediting" and that reduces the bearer "from a whole and usual person to a tainted, discounted one" (Goffman 1963 cited in; Link and Phelan 2001). Stigmatized people are perceived as deviant from prevalent or valued norms, and incapable of maintaining a healthy, productive life and meeting social (role) requirements (Susman 1994).

Stigma surrounding disability affects disabled children and their caregivers at the household, community and societal level (Barratt and Penn 2009; Hartley et al. 2005), resulting in social isolation, discrimination and reduced access to services. In Zimbabwe, people living with disabilities are extremely stigmatized and suffer from oppression and discrimination on a daily basis (Choruma 2007; Ndlovu 2013): “[...] It is a common perception within Zimbabwe that disabled people are passive and economically unproductive, and therefore constitute a ‘burden’ upon society” (Lang and Chadowa 2007: 6). Furthermore, disability is surrounded by myths concerning witchcraft, curses and God’s punishment for maternal promiscuity (Choruma 2007; Lang and Chadowa 2007; Marongwe and Mate 2007). Tolerance and social acceptance of disabled people are therefore limited (Peters and Chimedza 2000). Stigmatization is stronger towards mentally disabled people and in urban areas (Mpofu 2001; Mpofu and Harley 2002), and is much less prominent among close relatives of the disabled person.

#### *A weak state*

Core functions of the state are providing security, legitimization and ensuring welfare. States are seen as having failed when they do not perform on these three levels. State failure is often reflected in deteriorating education and healthcare systems, declining economic investment and growth, and thriving corruption (Rotberg 2003). Weak states (FSI 2011) are on the verge of collapse, requiring only a residing populace to revolt causing internal (armed) conflict to become a failed state (Loeb 2009: 13). Zimbabwe classifies as a weak state (Milliken and Krause 2002; Rotberg 2003). An unparalleled rise of inflation in the last decade (an estimated inflation rate of 231.000% in July 2008) led to the abandonment of the Zimbabwean dollar and (US) dollarization of the economy. Zimbabwe has “a consolidated budget deficit in excess of 80 percent of GDP” (Dore et al. 2008: 5) and (formal) unemployment rates of over 80%. Foreign and domestic investment have diminished and public services are hardly functioning (Besada and Moyo 2009). Political institutions are corrupt and controlled by security forces, the private sector and financial sector elites (Rotberg 2003).

In terms of laws and policy concerning disability issues, Zimbabwe had a “prominent regional standing in disability management and rehabilitation” in the early 2000s (Mpofu and Harley 2002: 27). The Disabled Persons Act of 1992 aimed at full inclusion of disabled people into Zimbabwean society, preventing discrimination and lifting stigma (Mpofu and Harley 2002). The state provided free public transportation for disabled people, disability allowances, Special Needs Departments and Psychological Services for schools, nine state rehabilitation centers and acknowledged 56 active

disabled people's organizations (Lang and Chadowa 2007; Mpofu 2001; Mpofu and Harley 2002; Van der Mark 2012). However, as Khupe (2010) states: "[...] in Zimbabwe disabled people have suffered worse oppression and discrimination during the last ten years as a result of the economic meltdown and political violence". Moreover, basic and healthcare services and special education facilities are tremendously affected (Loeb 2009; SIDA 2014; UN 2010), making the policy framework largely dysfunctional, despite the continuing efforts of the remaining disabled people's organizations.

#### **4.4 METHODOLOGY**

The study was conducted in Mutare, Zimbabwe's fourth largest town. The low-income groups among the 188,245 residents (ZNSA 2012) live in the city center, and four low-income 'townships' – Hobhouse, Chikanga, Dangamvura and Sakubva – with populations ranging from 80,000 (Sakubva) to 20,000 (Hobhouse) (City Link Mutare-Haarlem 2011). The research was carried out in cooperation with the local non-governmental organization S4S<sup>4</sup>, which provided access to its extensive database of 425 disabled children and their families from Mutare. The various respondents for the study were selected from this database. Two female Shona assistants supported the researcher. One had a strong academic background but limited practical experience with disability, and the other had the exact opposite qualifications.

##### **4.4.1 Methods**

This study incorporated various qualitative and quantitative methods. This mixed methods approach has shed light on the wellbeing outcomes, processes and structures that are at play in the caregiving field for disabled children. The data were derived from a quantitative structured survey (n=61), four participatory workshops (n=28), in-depth interviews (n=22) of 40 minutes on average, and quantitative secondary data.

The survey gathered information on the characteristics of the disabled child and the female caregiver, resources available, existing needs and employed strategies. The survey was established by breaking down the various concepts of the wellbeing framework using disability and care literature. A simple random sample (n=80) was drawn from the S4S database, anticipating a 20% non-response rate. The nonresponse rate was lower (7%), but another 13% of the sample had either moved or their child had passed away. Area-based survey sessions were held using a local classroom. The English questionnaire was to be self-completed by the caregivers, yet most women were reluctant to do so. The assistants then conducted the survey with groups of four women, explaining each question in Shona.

To gain a deeper understanding of the most important resources, goals, needs and strategies of female caregivers, four participatory workshops were held with an average of seven participants each, using four participatory techniques (ranking of needs, goals and concerns, drawing of a social network atom, ranking of strategies, ranking of material conditions). Participation was based on willingness after cooperation in the survey. All methods were designed to actively foster conversations and discussions on important issues for the caregivers. The assistants were present, guaranteeing the recording and translations of Shona comments.

Finally, in-depth interviews were held with 17 caregivers and five experts working in the disability field to shed light on more intangible issues; that is, the quality of life of the female caregiver and the child and the influence of structures. In addition to willingness, demographic characteristics of the child and the caregiver, such as type of disability and residency, were taken into account to create a wide representation of the population. Most interviews were done with an English/Shona interpreter. Finally, content analysis was performed on the few available policy documents. Secondary survey data (Choruma 2007) were used for triangulation. The data were analyzed using SPSS for the survey, ATLAS.TI for the interviews and manual categorization for the participatory workshops.

#### **4.4.2 The Respondents**

In total 61 female caregivers participated in the survey and a fraction of these women took part in the interviews or workshops. Table 2 shows the main characteristics of the caregivers and their children. All women lived in Mutare and could be considered urban. The aim was to include mainly low-income households in the sample. As reliable income data were not available from the database, we decided to select the women from low-income areas, assuming them to be primarily low income. This was confirmed through the survey and the in-depth interviews.

#### **4.4.3 Research Limitations**

A UN (2010) report estimates the number of disabled children in Zimbabwe at 469,000, which would come down to about 6900 in Mutare. Hence the 425 subjects in the database reflect only 6% of the disabled children in Mutare. However, it is the largest database we had access to and provided a large enough sample to derive respondents from. Also, the database consists of households that had actively sought support from an organization and therefore their experiences may not be representative for the entire population of caregivers of disabled children. Yet the database included many households that had not been actively involved in S4S work in the past years.

The wellbeing framework used has given an exploratory view of the disability and care field in Zimbabwe. However, the small sample size does not allow for significant causal relations and more research is required to accomplish this.

**Table 2.** Characteristics of caregivers in Mutare

Caregiver		
Relation to child	Mother	#50
	Grandmother	#4
	Sister	#2
	Aunt	#4
	Stepmother	#1
Age (mean: 40 years)	≤30 years	14.7%
	31–40 years	41%
	41–50 years	26.9%
	≥51 years	16.4%
Marital status	Single	14.8%
	Married, living with partner	54.1%
	Married, not living with partner	9.8%
	Divorced	1.6%
	Widowed	19.7%
Highest level of education	Primary	24.6%
	Secondary	67.2%
	Vocational	6.6%
	University	1.6%
Place of residence	Dangamvura	14.8%
	Town	6.6%
	Chikanga	21.3%
	Hobhouse	19.7%
	Sakubva	37.7%
Monthly income (Median: \$100)		
Child		
Age (mean: 13 years)	0–5 years	9.8%
	6–10 years	21.3%
	11–15 years	37.7%
	16–20 years	18%
	≥21 years	13.1%
Gender	Male	60.7%
	Female	39.3%
Type of disability	Multiple	21.3%
	Physical	42.6%
	Mental	19.7%
	Visual	3.3%
	Hearing	13.1%

## 4.5 MAIN FINDINGS

This study aims at developing a comprehensive understanding of the needs, resources and strategies of female caregivers and how stigma and the weak Zimbabwean state shape these. Below, we first discuss how the women experience those societal structures (wellbeing structures), followed by a presentation of the deployed strategies (wellbeing processes). Both sections discuss the resources commanded and lost (wellbeing outcomes), as these interact with wellbeing structures and processes.

### 4.5.1 Wellbeing Structures: Caregivers' Experiences with Stigma and a Weak State

Although 75% of the respondents state that specific relatives have a positive attitude towards their child, they claim to suffer from prevalent stigma on a daily basis. Their experiences confirm the literature (Lang and Chadowa 2007) stating that witchcraft, maternal failure and evil spirits are persisting beliefs in society. The children are discriminated by family members, paternal relatives, neighbors and church members. Paternal relatives and neighbors appear the least accepting, the most discriminatory and abusive. One mother of a severely mentally and physically challenged boy reiterates the response of her mother-in-law: 'She said: "If you leave this kid with us, definitely he is going to die"' (Interview 5, 30 September 2011). Although most of the abuse is directed towards the child, caregivers are also subject to it. Over 50% of the interviewees say that relatives and community members ignore, shout at, insult or blame them for the disability.

Not only stigma, but also the conditions of the weak state pose a significant burden upon the female caregivers. General living conditions in the country are hard and, according to the caregivers and the interviewed experts, the Zimbabwean government neglects disabled people. A first consequence of Zimbabwe's political and economic crisis is that basic services such as water and housing have deteriorated. Secondly, the state is reluctant to provide proper educational disability services (Interview 20, 14 October 2011) (Loeb 2009; UN 2010). Thirdly, the country has seen a major set-back in quantity and quality of medical services, resulting in: unaffordable or unavailable medical supplies and treatments, including assistive devices; underpaid and unmotivated physicians; and understaffed hospitals and clinics (Interviews 21 and 23, 17 October 2011). Finally, the Disabled Persons Act has not been ratified and no policies on disability have been put in place (Khupe 2010; Spink 2010).

Stigma and the effects of a weak state undermine the caregiver's life satisfaction. Over 80% of them mentioned during the interview to be *kurwadza*, Shona for all types of negative emotions including physical and psychological pain, discomfort, grief, boredom, anxiety and sadness. Discrimination of their child and themselves, and social isolation, put most women in a state of pain and grief. Furthermore, coping with poverty and deprivation is hard.

Our data also show that the contextual structures undermine the availability of resources, confirming the existing literature (Gona et al. 2011; Marongwe and Mate 2007; Mitra et al. 2013). Access to human, social, financial and material resources (wellbeing outcomes) is deplorable in Mutare. This influences the strategies that caregivers employ (wellbeing processes). The interviews bring forward three deployed strategies: reducing the effects of poverty; learning skills and training; and acceptance. We now discuss these strategies, their aim, the resources commanded and the influence of contextual structures.

#### **4.5.2 Wellbeing Processes: Caregivers' Most Deployed Caring Strategies**

##### *Reducing the effects of poverty*

In Zimbabwe, material resources are scarce and the survey shows that caregivers in Mutare are struggling to meet the material needs of the child and herself. The most pressing matters are housing, food and clothing. Unemployment, and thus a lack of finances, is the prime reason for material deprivation or dissatisfaction. Moreover, the caregivers lack proper access to social welfare. As a result of this scarcity, caregivers spend much time and give high priority to improvement of these dire conditions. They are preoccupied with *reducing the effects of poverty* on their child by enhancing their living environment and providing physical assistance, hygiene and health.

Basic household activities, or 'mothers' duties' as one participants group categorized it, are most important and comprise cooking food, washing clothes, spreading the bed and washing dishes. A close second is physical assistance/ hygiene, meaning assisting the child in their daily activities. Over 70% of the respondents' children need assistance on a daily basis; mainly with personal care (e.g. dressing, bathing and feeding) and medical care (e.g. giving medication and injections, changing dressings). Caregivers also provide physical assistance to maintain health (playing sports, doing physiotherapy). Only three caregivers receive assistance from their mother or a sibling.

Women perceive these activities as natural to childcare and to be a mother's obligation. Not only will the child physically benefit from good food, clothing and a healthy environment, but also the attitudes of other people to their child are expected to improve as physical appearance and hygiene are deemed essential to reduce stigma:

Smartness to me means a lot, when it comes to my child. So that other friends and neighbors can get close to her, when she is smart. (Workshop Sakubva, September 2011)

Caregivers consider *reducing the effects of poverty* most important for the child's wellbeing and spend most of their time on this. As they execute most activities themselves, learning skills and training is an important second strategy.

#### *Learning skills and training*

The lack of financial resources and basic medical services stimulates the caregivers to *learn skills* that enable them to care for their child themselves. These include skills to generate income, to perform medical treatment and to tutor the child. Over 73% of the respondents have learned skills to generate income. Most common is learning to grow vegetables, followed by rearing chickens. Women mostly generate income through such types of informal activities. Over 78% of the respondents learnt medical skills to provide at home, including administering medication, physiotherapy, and using assistive devices, but also communication skills such as sign language. Learning skills is linked to the scantily described training of the child at home. *Training at home* involves teaching the child basic life skills such as personal hygiene, household chores and income generation. In addition, caregivers teach children to read, write and do mathematics. Over one-half of the respondents are dissatisfied with the quality of education, in particular for disabled children, and believe that non-disabled children receive better education, as stigma is also present at school level. Caregivers desperately want their child to be independent and try teaching the child as much as possible.

Caregivers learn most skills from relatives or through exchange with other mothers of disabled children. Although women receive little direct assistance from their social network in caregiving, they do engage in informal exchange systems to lessen the burden of caregiving.

### *Acceptance*

The final strategy that emerged from the data is *acceptance*. Previously referred in work by Barratt and Penn (2009), Green (2007) and Kaplan (2010), this strategy is extremely important in the Zimbabwean context. The three research methods show that acceptance is what enables caregivers to care for their child. Over 92% of the survey respondents agreed with the statement that 'The fact that my child is disabled is of no importance to me; I have accepted him/her fully'. During the workshops, caregivers frequently mentioned how they value caring for and how their life revolves around the child. The in-depth interviews revealed the loving nature and acceptance that caregivers display.

The main inspiration for this acceptance was women's religious faith. Literature acknowledges that religious coping, whether classified as internal, organized or nonorganized, is a resource for caregivers (Hebert et al. 2006; Herrera et al. 2009; Miltiades and Pruchno 2002; Pearce 2005). Most Mutarean women consider their child a gift from God and very special.

The interviewees unanimously considered the response of others beyond their control and are convinced that God will have his reasons to have them experience this. This belief leads them to accepting. Religiosity appears to be the reason for the fact that worries about the child's future do not impact on the caregiver's psychological wellbeing. As one mother phrases it aptly:

If you pray to God, I believe in him, I give him my problems. I can't do anything, it's beyond my control, so I better pray than cry. He will help me, now and in the future. So I can sleep when I relief my chest with him. (Interview 11, 5 October 2011)

Being able to accept their child, the discrimination and the difficult circumstances in the country, with help of strong faith, sustains the caregivers. Internal and non-organized religiosity appear to prevail among caregivers; however, further research is needed for a thorough understanding of the relation between religiosity and acceptance.

Another basis for acceptance is comparing their situation with those of 'worse of women' such as childless women or women with more severely disabled children. The positive outcome of the comparison motivates caregivers to accept the situation:

There are other people maybe even in situations even more worse than G ... So sometimes we pray that at least he can walk for himself, he is presentable and everything ... So we just accept him, whatever is there. (Interview 1, 27 September 2011)

In conclusion, caregivers experience *kurwadza* and worry about the future. Yet their faith and acceptance are what sustains them and supports them in ensuring their child's wellbeing.

#### *Seeking support and income*

The literature review showed the importance of income generation and seeking various forms of support. Yet these strategies did not emerge from our data to be key to caregivers. Hence, the question arose of how Zimbabwean female caregivers seek external support and income and why they assign less value to these strategies.

Our caregivers dedicate a small component of their daily activities to income generating activities (IGA), mainly because Zimbabwe's dismal economic condition and high unemployment restricts possibilities for IGA. Caregivers perceive IGA as a fruitless endeavor and would rather spend their precious time at home on caring for their child. Caregivers with IGA are mostly self-employed and mobilize auto-learnt skills (as mentioned above) in activities such as maid services, retail of vegetables, poultry, refreshments or telephone cards, and temporary jobs.

Seeking informal, formal and medical support is prominent in the literature, yet Mutarean caregivers are not employing this regularly. They assert that they lack social or informal support and that their social network has limited resources, reducing the amount of available support. As one mother asserts:

Like sometimes my family, if today there is no money, then they will not give. But if they have money they will give and support me. But they are always struggling as well. (Workshop Sakubva, September 2011)

Another reason for not seeking social support, according to the caregivers, is that they would rather not beg for assistance but expect friends and family to come forward themselves.

Limited financial resources and time cause seeking formal and medical support to be rather futile. This is further complicated because of inadequate medical and professional disability services in the country. Hence, the interviewees regard these efforts as time-consuming, a waste of money and enormously disappointing.

The above shows that in Zimbabwe where 'external' financial, social, medical and educational resources are limited, caregivers rely on and subsequently attach a higher value to self-provided 'physical' and human resources. This explains the importance of basic household activities, learning skills, and educating the child as the most important strategies to realize the wellbeing of their disabled child.

#### 4.6 CONCLUSION

This article explores caring strategies of female caregivers of disabled children in Mutare, Zimbabwe. We expected these strategies to be shaped by Zimbabwe's condition as a weak state and the strong stigma associated with disability in the country. Although it has been on the forefront of disability activism, limited research addresses the experiences of caregivers after the political and economic downfall of Zimbabwe. Our analysis is guided by the wellbeing approach that fosters a comprehensive understanding of people's needs, resources and strategies, and how these are shaped through societal structures.

The study shows that Zimbabwean caregivers operate largely without external support. As formal state and non-governmental organization facilities have deteriorated and social support networks are limited, women deploy three strategies to provide care and comfort to their child: *reducing the effects of poverty* by deploying basic household activities and providing health/hygiene to their child; *learning skills* to provide the necessary medical care; and *training* the child for independence. The lack of external support causes stress, pain and feelings of neglect among women. A fourth developed strategy, *acceptance*, addresses this and supports women in finding peace with their situation. Faith is the base for this acceptance and plays an important role in realizing wellbeing. Strikingly, IGA play a minor role, mainly because of high caring demands and poor economic conditions in Zimbabwe. In conclusion, women are mostly self-reliant and their strategies focus on enabling themselves to take care of their child.

In this article, we only touch upon the quality of life of caregivers and disabled children. More research on this would allow understanding of the causal relations between *kurwadza*, stigma, poverty and quality of life in countries such as Zimbabwe. Similarly, more knowledge is required on demographic and disability differences between caregivers. Despite these limitations we do think our findings are valuable to academic and policy debates on disability and care.

First of all, the results of the study demand a more central role of faith or religiosity in disability and care studies as well as in wellbeing approaches. More attention for religious coping (Herrera et al. 2009) in particular is warranted. Secondly, the findings emphasize the importance of context in understanding disability and care. Therefore, the academic debate on disability and care, in our opinion, should focus on examining questions related to the impact of various contexts on disability and care, including the role of faith and self-reliance. Furthermore, knowledge is required on how women learn skills and train their children, and the effect of programs that work towards social integration. Finally, this first attempt to deploy a wellbeing approach to understand the strategies of caregivers of disabled children has indicated that the approach is valuable to map subject experiences as well as object experiences in a structured way. In terms of policy and practice debates, our findings stress the importance of interventions that address the realities, resources and strategies of caregivers in a poverty context. This means developing strategies that address poverty conditions at least as much as the actual disability of the children itself. Examples would be development of IGA that do allow combined care and labor, and establishing those facilities that are most needed such as housing, food and (home-based or external) day-care.

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- <sup>1</sup> In terms of the definition of disability prevalent in Zimbabwe, all three main models of disability identified in disability studies are of influence. The country portrays the moral model in popular beliefs and uses both the medical and social model of disability in its policies (Government of Zimbabwe (1992). Disabled Persons Act. Harare, Government of Zimbabwe.) We therefore use the holistic definition of disability of the World Health Organization (ICF-CY: International Classification of Functioning, Disability and Health for Children and Youth) published on the organization's website (<http://www.who.int/classifications/icf/en>).
  - <sup>2</sup> This study is part of a larger research conducted for the University of Amsterdam. This also incorporated the subjective experiences of the caregivers in terms of quality of life. For argument purposes, this study focuses only on resources, strategies and structures.
  - <sup>3</sup> In disability and care research, this division is not commonly used. However, by reviewing the literature on frequently employed (coping) strategies, an understanding of needs and resources is gained.
  - <sup>4</sup> See [www.sport4socialization.org](http://www.sport4socialization.org). S4S tries to improve the quality of life of disabled children in Africa through adapted and integrated leisure activities, individual child support, income-generating projects and parent support groups.