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## **Against All Odds**

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# CHAPTER 2

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Conceptual Framing

In order to gain insight into the care of a disabled child in the context of poverty, relevant concepts which need clarification are poverty, care and disability. In addition, as this research aimed at understanding mechanisms for social change and improving wellbeing, a conceptual framework that could capture the daily realities of female carers living in poverty as well as provide a direction for change was needed. Due to a scarcity of literature on the topic, no universal conceptual framework exists on carers' experiences living in poverty. Therefore, in this thesis, the wellbeing framework developed by the University of Bath was applied to provide conceptual guidance. In addition, a Participatory Action Research (PAR) approach was adopted to foster social change.

As the context of poverty takes center stage in this thesis, in this chapter, firstly the wellbeing framework is explained which encapsulates an understanding of poverty. Then, the provision of care by the main actors in this thesis, the female carers, is framed by exploring the concept of care. Next, multiple understandings of disability are discussed. Subsequently, PAR-theory and motivations for choosing PAR in this context of poverty (wellbeing), care and disability are explicated. Lastly, an adaptation of the wellbeing framework is presented, tailored to the specific complexity of caring for a disabled child in a resource-poor context and to the use of PAR.

## **2.1 WELLBEING: A MULTIDIMENSIONAL UNDERSTANDING OF POVERTY**

The Wellbeing in Developing Countries (WeD) program (2002-2007) of the University of Bath developed a conceptual and methodological framework for "understanding the social and cultural construction of wellbeing in developing countries" (Gough and McGregor 2007: 316). This wellbeing framework contributes to the understanding of the multidimensional character of poverty<sup>1</sup>. It has emerged as a response to conventional development frameworks which tend to focus on money-metric poverty measurement (Gough and McGregor 2007). Poverty is herein defined in terms of lack of income or consumption. This narrow conceptualization of poverty, however, has progressively been challenged.

In the 1990s the UN introduced the Human Development Index (HDI) which incorporated not only income, but also averages of education and life satisfaction. "The HDI in turn was inspired by the basic needs index of Peter Townsend (1979), as well as the capabilities approach by Amartya Sen (1985)" (Pouw and Gilmore 2012: 17). The latter adopted a notion of poverty defined as a deprivation of capabilities.

Capabilities are, according to Sen, the functionings –‘beings and doings’– a person is able to achieve, and the substantive freedoms the person enjoys and has reason to value (1992). Sen’s initial approach broke with the traditional economic approach and gave way to a multifaceted and wider definition of poverty (Gough and McGregor 2007). People’s freedoms, opportunities and inequalities were herein acknowledged as important factors of a person’s wellbeing (Pouw and Gilmore 2012).

The wellbeing framework attempts to integrate all the different notions of poverty, such as income poverty, basic needs and capabilities deprivation into a wider concept. It therefore focuses on the human being, and incorporates the objective circumstances, the subjective experiences of a person living in poverty, and the influential societal and institutional processes (McGregor 2006; Pouw and Gilmore 2012). Wellbeing (Figure 1) is thus understood as the result of the interaction between 1) the available resources; 2) the level of fulfillment of a person’s needs and goals with those resources; and 3) the value a person attaches to the goals they achieve and to the processes in which they engage (Pouw and Gilmore 2012). Societal conceptions and context integrally shape these components (McGregor 2006).

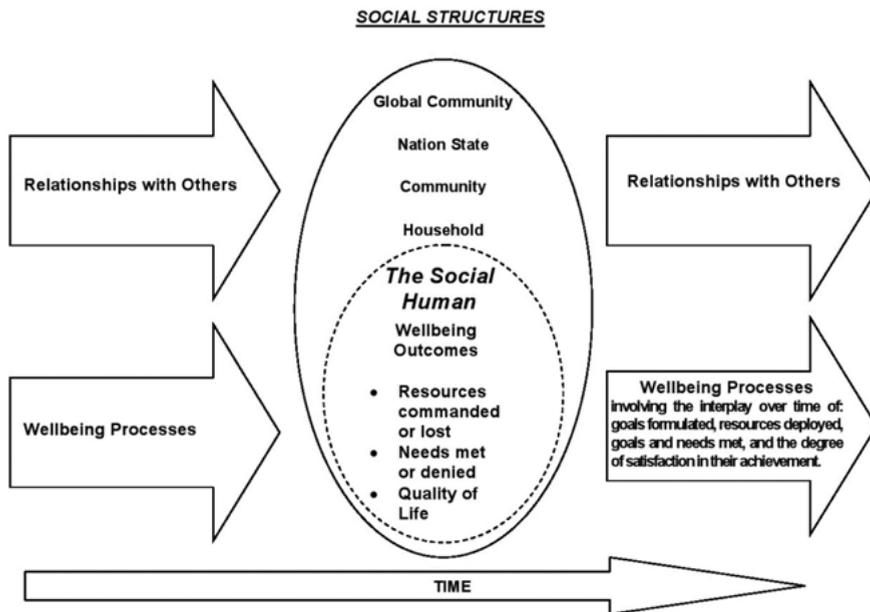


Figure 1. A wellbeing framework. Source: McGregor (2006: 25).

Three main wellbeing research categories exist: wellbeing outcomes, wellbeing processes and wellbeing structures. Wellbeing outcomes include resources commanded and lost, needs met and denied, and quality of life achieved. These outcomes are in turn influenced by wellbeing processes and wellbeing structures through time. The former refers to the processes of formulating goals and employing strategies to reach these goals. The latter shows the relationships in which human beings are engaged on a household, community, state and global level (McGregor 2006).

The wellbeing framework provides a multidimensional approach and acknowledges the fact that caregiving is shaped by complex structural environments such as poverty. The focus thus not only lies on disability. It can incorporate contextual factors such as stigma, access to resources, and social relationships. The issue of disability and care can hereby be placed in a broader developmental framework. Before further developing this, we will first have a look at what both care (Section 2.2) and disability (Section 2.3) entail conceptually and in the Southern African context.

## 2.2 POLITICS OF CARE

### 2.2.1 Care as a Concept

Care as a concept in literature remains contested and thus knows many different versions depending on its usage and context. In particular (feminist) theorists on the ethics of care, such as Tronto (1993), Noddings (2013) and Held (2006), have made significant contributions to thinking about care. In general, consensus exists on how care – at the very least – involves the performance of *caregiving*, as in the activity or work involved. There is less agreement however, on whether care can be conceptualized as more than this. For example, Noddings (2013) discusses the importance of attitudes accompanying the task of providing care, such as carers' perceptions of and feelings towards the person in need. Bubeck (1995) on the other hand emphasizes the mere act of fulfilling a person's needs in which this affectionate relation is not necessarily required:

Caring for is the meeting of the needs of one person by another person, where face-to-face interaction between carer and cared-for is a crucial element of the overall activity and where the need is of such a nature that it cannot possibly be met by the person in need herself (Bubeck 1995: 129).

In Held's view (2006), care extends well beyond the personal, face-to-face sphere and the act of caregiving Bubeck mentions, as, she argues, it also addresses "the social ties that bind groups together, to the bonds on which political and social institutions can be built, and even to the global concerns that citizens of the world can share" (31).

In relation to caring for a disabled child in the context of poverty, this research is primarily aimed at the processes of care specifically between a female carer providing most care on a daily basis, whether biologically related or not, and a disabled child in her household. A relatively personal notion of care was therefore maintained, complemented with Tronto and Fisher's (1990) classification of care, which stresses its multidimensional nature. They distinguish between four phases:

[...] *caring about*, i.e. recognizing a need for care; *caring for*, i.e. taking responsibility to meet that need; *care giving*, i.e. the actual physical work of providing care; and, finally, *care receiving*, i.e. the evaluation of how well the care provided had met the caring need (Tronto 2010: 160).

This classification recognizes subjective motivations and feelings, meeting basic human needs and personal labor, whilst simultaneously providing ample room to acknowledge broader caring relations, and influencing factors such as poverty. Without specifically aiming to classify the care of Southern African female carers, this present thesis is mostly concerned with the practices of caring for and care giving.

### **2.2.2 Care in the Southern African Context**

Care, and in particular who is responsible for care of people in need, is often a highly politicized matter. Since the 1990s, under the influence of emerging neoliberal ideas, many Southern African governments have exacerbated the burden of care of people caring for their more vulnerable family members. In post-apartheid South Africa (the context of one of the case studies in this thesis), a promising progressive policy framework was rolled out on the premise of universal equity. The newly installed (black) government acknowledged the needs of vulnerable groups in society and its own role in meeting these needs (SALS 2007). The government drafted, among others, a National Programme of Action (NPA) based on the United Nations Convention on the Rights of the Child. With special reference to disabled children, it upholds Article 23 of the Convention:

States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child (CRC, UN 1989).

Bearing Tronto and Fisher's (1990) classification in mind, this reveals how the South African government positions itself at a relative distance: it recognizes the right of the disabled child (*caring about*), but expects others to be responsible (*caring for*), and provide care (*care giving*). The government might be able to extend some assistance – *caring for* – but subject to available resources. In practice, this resulted in a mere assisting role for the government. The adoption of a neoliberal framework meant the introduction of stringent means-testing for social safety nets, user-fees for social services, and privatization of supply services; all causing constrained access for disadvantaged communities (Midgley 1995). Moreover, to this day, the impact of progressive social policies such as the provision of special education facilities remains minimal, leaving the burden of care mainly with families.

In Zimbabwe (the context of the other case study in this thesis), after its independence in 1980, the Robert Mugabe led government made enormous efforts expanding social services for universal coverage. However, in the early nineties, the country adopted the Structural Adjustments Programmes (SAPs) leading to neoliberal measures such as austerity and privatization, hereby further marginalizing many black communities (Muchacha et al. 2016). Today, Zimbabwe acknowledges the special needs of children with disabilities and the variety of actors responsible for meeting these.

Strengthening the rights-based approach to programming, where the family, community, local authorities, civil society, and the state are viewed as duty bearers, and must commit to upholding children's rights (Government of Zimbabwe 2010: 20).

Following Tronto and Fisher's (1990) classification, the country seems to address all four phases of care. Yet, in practice, the Zimbabwean state has grossly neglected its duty bearing role (SIDA 2014), again leaving the burden of care primarily with families.

Inopportunately, family life and kinship systems in Southern African countries are not as close-knit as they might once have been. Colonial and apartheid politics have tremendously disrupted family life, especially among the black majority population

(Bozalek 1999; Levin 2006; Lyons 2002). Male rural-urban migration, socio-economic marginalization and prolonged (independence) battles and war weakened the caring capacity of many families. Additionally, in many African countries, family cohesiveness has since then been further compromised by high prevalence of poverty, HIV/AIDS, and the breakdown of traditional systems (Budlender and Lund 2011; Gandure 2009; Gona et al. 2011).

This context of an underperforming state apparatus and severely disrupted family life in general poses enormous strain on women since they are traditionally seen as the primary carers in (black) African communities (Akintola 2006; Barratt and Penn 2009; Núñez Carrasco et al. 2011). They often hold an unequal position in the household and now carry a triple burden in the survival of the family. Not only do they carry the full responsibility for the biological and social reproduction of the family in terms of giving birth, child care, health issues and domestic work. They are also expected to contribute substantially to the economic survival of the family (Bozalek 1999; Lorber 2010; Tamale 2004). Whereas many African women rely on social support in order to fulfill this multitude of obligations, women with disabled children usually cannot. They face severe discrimination and lack of support in the (extended) family sphere and in the community (Lansdown 2002; van Pletzen et al. 2014). In fact, fathers are reported to often evade their parental duties when a disabled child is born (ACPF 2011; Barratt and Penn 2009; Levin 2006). Consequently, the particular (gendered) politics of care in Southern African countries result in significant power discrepancies, put the onus of care on female carers, and significantly mold their experiences and opportunities.

## 2.3 DISABILITY MODELS

### 2.3.1 Three Conceptual Models

Within Disability Studies three main models of disability have been identified throughout history. One of the most widespread models is the medical model. The medical model arose during the Western Renaissance and regards disabled people as having a purely medical problem which prevents people to successfully perform in society. "The medical model eschews moral model explanations, but keeps people with disabilities dependent on society for charity and care" (Mackelprang 2010: 88). Particularly during neoliberal reforms in the 1980s and 1990s, many countries officially adopted this definition of disability, including several Southern African countries such as Zimbabwe and South Africa (ACPF 2011; Choruma 2007). Neoliberalism needs each citizen to be economically useful and to fulfill their citizenship duties. Disabled people are thus seen as uncompetitive and have to seek services that can make them whole,

functional and competitive again. It is herein assumed any malady is “for the most part . . . a personal problem related to failure to adapt properly” (Murphy 2010: 226). The search for treatment and a cure is therefore prominent in this model. The needs and goals of disabled people (and their carers) are perceived to be concerned with rehabilitation and treatment. Many governmental and development policies around the world were and still are merely focused on providing these rehabilitation and treatment services.

Alternatively, the moral model of disability has existed through much of recorded history (Mackelprang 2010). It designates disabled people as people with deficiencies caused by various reasons often surrounded by myths such as witchcraft and promiscuity. In many countries around the world, popular beliefs still resemble a moral model (e.g. ACPF 2014; Huang et al. 2012). Disabled people are commonly seen as a burden which results in social isolation and discrimination. This leaves disabled people often reliant on charity and with limited opportunities for self-sufficiency.

The social model emerged in the last decades in stark contrast to the prior models (Oliver 1996). This model views disability not as a moral or medical problem but as a mere result of the social exclusion, discrimination and oppression that people with an impairment are facing on a daily basis (Hughes 2009; Oliver 2013). The social model redefines the concept of disability as “a social construct, that is, a consequence of historical, material and social conditions, which create a disabling society that marginalizes and excludes people with a disability” (Mays 2006: 150). Most challenges that disabled people face are believed to occur due to external factors such as societal beliefs and material infrastructure (Mackelprang 2010; Oliver 2013). These can for example cause reduced social support and relationships, and limited access to education, healthcare and other services and information. What is needed according to this model is an eradication of discrimination, combined with a change of societal structures.

Various critiques of the social model have however emerged during recent years, three of which are significant. First, a commonly heard critique is the fact that it seems to ignore the body and the self. Proponents of the social model state that “disablement is nothing to do with the body. It is a consequence of social oppression” (Oliver 1996: 35). Critics argue that though it is important to acknowledge the social circumstances that foster disability, the physical reality of disability and hereby the necessity of treatment and other services facilitating the body cannot be ignored (Gabel and Peters 2004). Another critique is seen in the exclusion of important dimensions of disabled people’s

lives and knowledge. Research in disability studies applying the social model tends to focus on descriptive accounts of external factors such as policies without taking into account the subjective experiences and knowledge of disabled people themselves (Gabel and Peters 2004; Oliver 1996; Shakespeare and Watson 2001). This brings us to the last critique which argues that the social model does not fully recognize the way agency and structure are interconnected. Disabled people are, according to Shakespeare and Watson (2001), no passive citizens in society who allow themselves to be subjected to oppression and discrimination without resistance. While societal structures might create the notion of disability, disabled people are also part of these structures and able to influence them.

### **2.3.2 Conceptual Models in the Southern African Context**

Though the various models of disability emerged in Western history and theory consecutively, in Zimbabwe and South Africa all three models are still of influence. Zimbabwe portrays the moral model in popular beliefs and still uses the medical model of disability in its policies; yet the particulars of the social model are also visible. Not only are the social and cultural barriers mentioned in the definition of a disabled person in its Disabled Persons Act (DPA) (Zimbabwe Government 1992), the main issues the DPA wants to tackle share great similarities with the social model, such as inclusive employment and human development.

In South Africa, the social model has gained prominence in social policies and legislation since 1994 (ACPF 2011), and particularly since it published its landmark policy document on disability equity in 1997; i.e. the Integrated National Disability Strategy (INDS) (McClain 2002; OP 1997; SAHRC 2002). The main pillar of the INDS is reconstruction of South African society to address the needs of disabled people, self-representation, and integrated and sustainable policies on disability (Lansdown 2002; OP 1997). Yet, South African society is still embedded with cultural beliefs surrounding disability such as witchcraft and ancestral punishment (Barratt and Penn 2009; Levin 2006; Masasa et al. 2005). Furthermore, as a result of policies based on the medical model for decades, such as outsourced rehabilitation and living, disabled people continue to be excluded from their communities and mainstream activities.

This thesis seeks to build on the social model of disability while acknowledging the various interpretations still prevalent in Southern African societies. In order to do so the holistic disability definition of the World Health Organization<sup>2</sup> is maintained, which stipulates that disability be viewed as the “outcomes of interactions between health conditions (diseases, disorders and injuries) and contextual factors” (WHO 2002: 10).

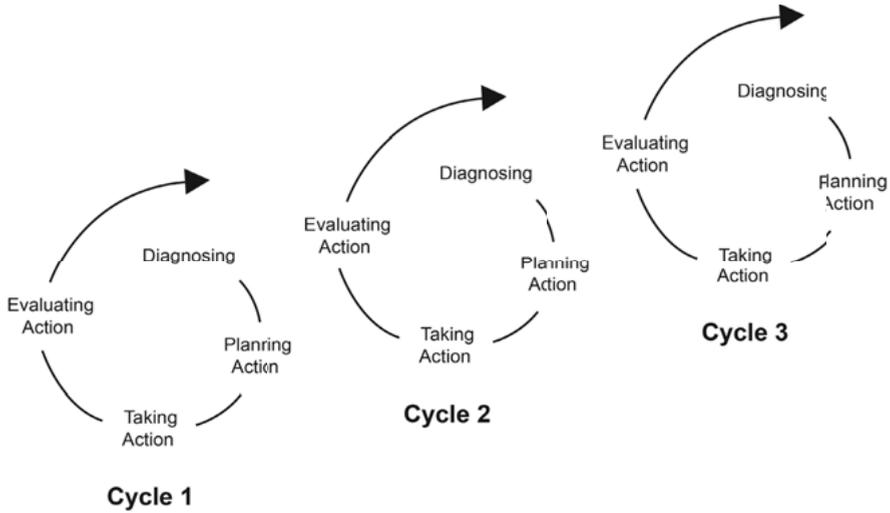
## 2.4 PARTICIPATORY ACTION RESEARCH

Having discussed the relevant concepts above, i.e. wellbeing (poverty), care and disability, this section introduces Participatory Action Research, and discusses why a PAR approach is important to study the intersection between the three concepts and to foster social change.

Participatory Action Research (PAR) has its roots in both Action research (AR) and Participatory research (PR) which have gained ground over the last decades in development practices (De Koning and Martin 1996; De Vos et al. 1998; Khanlou and Peter 2005). It has many origins and has been influenced by various theories and initiatives over the years, which makes it difficult to define a linear history of PAR. It is clear however that the upsurge of anti-positivist epistemologies and the renewed appreciation for local knowledge influenced its emergence tremendously (Chambers 1997; De Koning and Martin 1996; Khanlou and Peter 2005). PAR originated in Latin-America, Asia and Africa with Paolo Freire as one of the main contributors to its intellectual foundation (Cornwall and Jewkes 1995; De Koning and Martin 1996). Freire insisted on an awareness of power disparities and on combining research with social action to destabilize the status quo (Chambers 1997).

According to Chambers (2010), participatory methods and action research are exemplary for the paradigm shift from a ‘things’-oriented to a people-oriented development discourse. Instead of searching for a ‘true’ and independent reality with standardized methods in controlled conditions, PAR is aimed at “understanding and expressing the local, complex, diverse, dynamic, uncontrollable and unpredictable (*lccduu*) realities experienced by many poor people” (Chambers 2010: 3). The underlying overall goal of PAR, consistent across disciplines, is as Lake and Wendland (2018: 15) identify, “the improvement of human life”, or as Nicolaidis and Raymaker (2015: 168) phrase it, the improvement of “health and wellbeing through action”.

For this reason, PAR is designed to collectively generate local and relevant knowledge, and subsequently act on it by designing interventions that reflect the daily realities of the people involved (Abma et al. 2019; McNiff 2002; Rifkin 2001). It does so through iterative cycles. Generally these cycles are comprised of four stages (Figure 2), with varying titles; diagnosis (or conscientization or analysis), planning, action and reflection (or evaluation) (Coghlan 2019).



**Figure 2.** Cycles of Participatory Action Research. Source: Coghlan 2019

The first phase entails the process of learning to become aware (*conscientização* (Port.) = consciousness raising) or acquiring an in-depth understanding of the world, in particular of (unequal) political and social conditions. The planning and action phases focus on developing projects to challenge these conditions. The reflection phase assesses the processes and outcomes of the action projects and hereby informs the subsequent phase. By way of these cycles, PAR attempts to generate more societal impact from research practices. It does so by aligning research with local needs, putting findings more easily to use, and empowering participants to collectively address challenges (Lake and Wendland 2018). A PAR-project thus aims to incorporate local people into the research process as co-researchers and put them in charge of decision-making and implementation (Golooba-Mutebi 2005; Lake and Wendland 2018). As Cornwall and Jewkes (1995) assert: “The key difference between participatory and conventional methodologies lies in the location of power in the research process” (1667).

Given the intent of this thesis to work towards empowerment and wellbeing, and to simultaneously gain an in-depth understanding of mothers’ experiences with care in poverty, PAR was a well-suited choice for the second case-study. PAR provides the opportunity to focus on the women’s realities, aspirations and priorities to be interpreted by themselves and not by the ‘outsider’ researcher, whilst at the same time aiming for social change which will fit their daily realities and therefore have a bigger chance of being inclusive and successful.

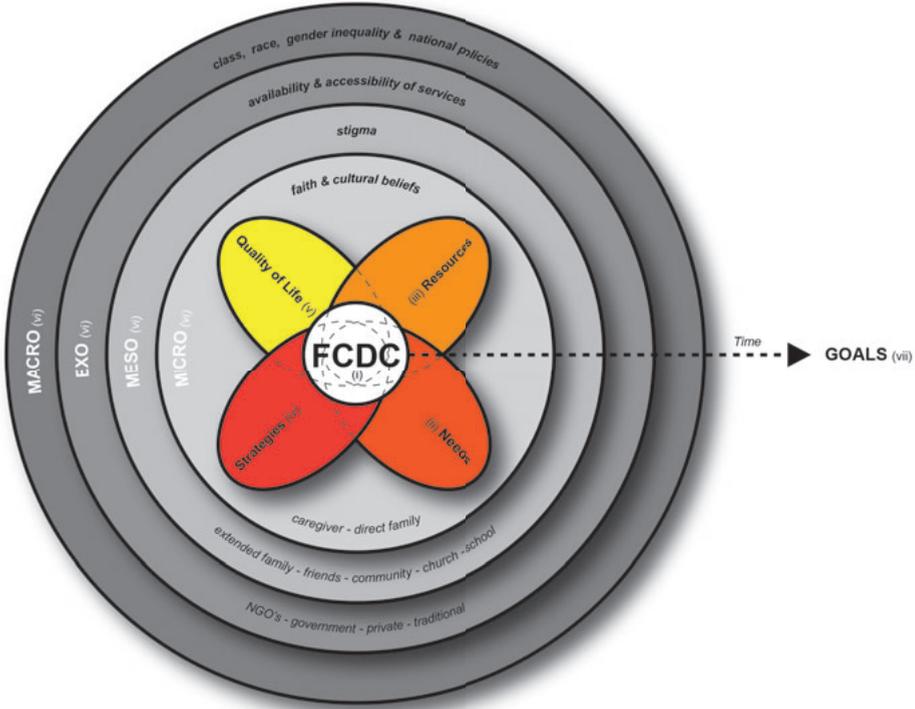
## 2.5 CONCEPTUAL FRAMEWORK

Based on the explanation of concepts and PAR approach, this section presents an adaptation of the wellbeing framework tailored specifically to the complexity of caring for a disabled child in a Southern African resource-poor context. As this research was exploratory in nature due to the limited literature available on the topic, this conceptual framework served as a scoping and guiding tool as to which concepts to bear in mind, rather than as a methodological roadmap.

The wellbeing framework could be well adapted to the Southern African disability context because it could incorporate the three conceptual disability models and consider the various critiques of the social model. The adapted model (see Figure 3 on next page) not only encapsulates the influence of popular beliefs (moral), the rehabilitation and treatment services and facilities (medical), and the societal structures such as national policies (social), but also the subjective experiences and individual strategies and actions.

Starting point are female carers of disabled children (FCDC) (see *i* in Figure 3) from Southern African resource-poor urban settlements. Following the original wellbeing framework, it was assumed that in order to fulfill the needs (*ii*) of their child, female carers employ certain resources and strategies (*iii* and *iv*). The fulfillment of needs, available resources and employed strategies affect their perceived Quality of Life (*v*) and these four mutually influence one another. Inspired by the ecological model by Bronfenbrenner (1986; 1992), the various structures (*vi*) were assumed to shape all of the above elements (*i* to *v*). Lastly, in the South-African case-study, goals (*vii*) would follow over time to change their level of wellbeing and develop meaningful interventions.

By connecting the wellbeing framework specifically to existing knowledge on disability and care in various contexts (see Chapter 4 for thorough overview), the four structures could be specified to bear in mind relevant concepts relating to mothers of disabled children. On the micro-level female carers' faith and the cultural beliefs surrounding disability, care and motherhood were assumed to be influential. Disability stigma came to the fore in literature as highly significant on the meso-level. The exo-level related mostly to the availability and accessibility of different kinds of support services. Finally, class, race and gender inequality, and national policies on disability, care and poverty were defined as influential factors in caring for a disabled child.



**Figure 3.** Adaptation of the Wellbeing Framework: Disability, Care and Poverty Model

<sup>1</sup> At the start of this PhD-research (2014), the University of Bath was in the process of finalizing a four-year research program to test the wellbeing framework empirically in Zambia and India. The adaptations based on this empirical work were therefore not part of this research.  
<sup>2</sup> ICF: International Classification of Functioning, Disability and Health