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ACCOUNT

Chapters 4 till 8 are based on co-authored articles published in or under review with peer-reviewed international academic journals.

Chapter 4

Elise Jantine van der Mark & Hebe Verrest (2014). Fighting the Odds: Strategies of Female Caregivers of Disabled Children in Zimbabwe, *Disability & Society* 29(9): 1412-1427. DOI:10.1080/09687599.2014.934441

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Chapter 5

Van der Mark E.J., I. Conradie, C.W.M. Dedding and J.E.W. Broerse (2017). How Poverty Shapes Caring for a Disabled Child: A Narrative Literature Review, *Journal of International Development* 29(8): 1187–1206. DOI:10.1002/jid.3308.

Chapter 6

Elise J. van der Mark, Ina Conradie, Christine W.M. Dedding & Jacqueline E.W. Broerse (2018). 'We Create Our Own Small World': Daily Realities of Mothers of Disabled Children in a South African Urban Settlement, *Disability & Society* 34(1): 95-120. DOI: 10.1080/09687599.2018.1511415

Chapter 7

Van der Mark E.J., I. Conradie, C.W.M. Dedding and J.E.W. Broerse (2019). Exploring Adaptation and Agency of Mothers Caring for Disabled Children in an Urban Settlement in South Africa: A Qualitative Study. Accepted for publication by *Women's Studies International Forum*.

Chapter 8

Van der Mark E.J., T. Zuiderent-Jerak, C.W.M. Dedding, I. Conradie and J.E.W. Broerse (under review). 'I Am a Brand-New Me': The Unlikely Transformation towards Wellbeing among Mothers of Disabled Children in South Africa: A Participatory Action Approach. Submitted to *Journal of Southern African Studies*.

PREFACE

Over a decade ago, while I was working as a cultural project manager in Zimbabwe, a first seed was sown for the book you are holding in your hands. In hindsight, this is when my interest in the daily realities of women living in Southern Africa, and in particular those caring for a disabled child grew. Little did I know at that time; I would eventually write a dissertation about it.

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— During those days (2007-2008), Zimbabwe was in the midst of an unprecedented socio-economic crisis. Basic commodities such as bread, milk, flour and eggs were continuously out of stock; money (coins and notes) was so scarce, people queued for days at the bank; fuel supplies were drying up which caused (public) transport to almost come to a standstill; and water and electricity were supplied intermittently, usually only during the night, causing millions of Zimbabweans sleepless nights due to household chores at ungodly hours.

As I was so privileged to receive continuous government supplies of fuel, I was able to cross the border to Mozambique every other week to go grocery-shopping, for myself and for many of my colleagues. It goes without saying this created some mixed feelings within myself, both unease and gratitude for being able to do so, as well as jealousy and spite among co-workers. They subsequently showed me what life in Zimbabwe was really like; living without the support of non-governmental organizations (NGOs) and government. I was struck by the grinding, continuous strain of daily survival, while at the same time in awe with the creativity displayed. Particularly women, being the main caregivers, breadwinners and peacekeepers of the family, were in my opinion performing nothing short of miracles. How were they able to feed, clean, educate and care for their families in such damaging circumstances? And how did they not – as I thought I would – lose their mind, fall ill or be left heartbroken? These questions had been lingering in my mind for some time, when I came across an NGO working with children with disabilities and their female carers. It seemed to me, while participating in the NGO's activities, these particular women were dealt a hand even worse. Caring for a disabled child whilst living in poverty came across as a spectacularly disadvantageous combination, causing severe marginalization.

Several years later (2011), I did not have to think long to come up with a topic for my Master's fieldwork and thesis. I knew instantly I would return to Zimbabwe and explore the experiences of women caring for a disabled child. I wanted to understand how they lived their daily lives, how they were feeling, how they were practicing and experiencing care, which challenges they were facing, and which needs they had.

The exploratory study I subsequently undertook provided unexpected and valuable insights, however, much to my dismay, its purpose remained theoretical. My thesis could not make a valuable contribution to the amelioration of the living conditions of the women and their children.

Fortunately, again a few years later (2014), while I was living in South Africa, I got the opportunity to conduct more research with mothers of disabled children. This time, I wanted to make sure it would have the potential to contribute positively to the lives of the women, and possibly beyond. For this purpose, I adopted a Participatory Action Approach which emphasizes co-creation of knowledge, collaborative analysis of issues and taking shared action to tackle these issues. Thus, the book you are holding in your hands is the result of not only my continuous efforts to explore and understand mothers' daily realities, but more so, *their* willingness to accept me into their lives, share their stories and together re-shape their wellbeing, as well as mine. They have my eternal gratitude.