

BREAKING SOLITARY GENDERED DISABILITY CARE IN SOUTHERN AFRICA

TOWARDS DISABILITY AND CARE INCLUSIVE DEVELOPMENT

SUMMARY

Southern African women commonly bear primary caregiving responsibility for a disabled child whether being the biological (grand)mother, sister, or aunt to the child. Within poor socio-economic contexts, these ‘mothers’ face a tremendously difficult existence that is compounded by intersecting challenges of disability, stigma and poverty. This forces them to opt for a solitary form of caregiving – hence, making them invisible to policymakers and institutions. Yet, care and disability are increasingly being recognized as crucial elements for care inclusive development. This brief puts the spotlight on the outcomes of years-long research with Southern African mothers caring for a disabled child. It argues that to move towards a disability and care inclusive development in Southern Africa a relational approach is needed which acknowledges all factors shaping mothers’ and children’s wellbeing. A relational understanding can foster a shared responsibility for fighting discrimination and abuse, break the solitary character of disability and care, and ultimately generate better life outcomes for disabled children and their caregivers.

DISABILITY CAREGIVING IN POVERTY

Women worldwide commonly bear primary responsibility for caring for a disabled child. Especially in contexts where women’s social role is constructed along patriarchal lines, such as in Southern Africa, the caregiving of a disabled child is often solely placed on the shoulders of mothers, sisters, grandmothers, and aunts.*

The limited information on the experiences of mothers of disabled children in poor socio-economic contexts suggests a difficult existence in which mothers face various financial, physical, and psychosocial problems (1). Caring for a disabled child is a daily juggle between the child’s physical, medical and emotional needs; personal and social obligations and responsibilities; expectations and requirements from the outside world; and the physical and mental wellbeing of the caregiver (2).

Contextual factors such as quality of and access to healthcare services, availability of assistive devices, and infrastructure, as well as additional disadvantages relating to deep-seated socio-cultural norms, gender stereotypes, care expectations, and poverty, create further challenges for women that perpetuate their roles when caring for their disabled child.



BASIC RIGHTS PROVISION OF DISABLED CHILDREN IN SOUTHERN AFRICA

Primary education	< 10%
Under-five Mortality	up to 80%
Basic Healthcare	Limited access
Assistive Devices	Between 0,4-33%
Rehabilitation	Limited access
	e.g. 1 physiotherapist for 45000 people in South Africa

Box 1. Facts and figures basic rights provision

Poverty has been particularly recognized to stand in a two-way relationship to disability which further complicates caregiving practices. Disabled children and disabled people are more prone to live in poverty, as it is considered both a cause and a consequence of disability (3). Loss of income, additional costs due to medical needs, and economic exclusion faced in society are just a few reasons why “disabled people are often the poorest of the poor” (4). Moreover, the persistent and severe stigma surrounding disability within Southern Africa aggravates the lived realities of disabled children and their mothers. In sum, they face tremendous inequalities on a physical, social, financial and educational level and remain to be among the most marginalized and ill-treated groups in Southern Africa (5).

Integrating their experiences and needs into research and policymaking is therefore critical not only from a moral perspective, but also for the achievement of equitable inclusive development, touching upon SDG's 1 to end poverty, 3 ensure and promote health and wellbeing, 5 achieve gender equality and empower women, and 10, reduce inequality (6).

LIVED EXPERIENCES OF DISABILITY CAREGIVING IN POVERTY

Our years-long (2014-2019) participatory action project conducted in South Africa and Zimbabwe set first milestones into engaging mothers of disabled children from resource-poor contexts into scientific research. This project put mothers of disabled children centre-stage by inviting them to take ownership of the project and investigate their own experiences and practices whilst aiming for social change. This participatory approach enabled us to gain insights into the tremendously difficult existence of mothers and into how they manoeuvre in and adapt their caregiving practices to it (7).

Relational Reality - Compounded Challenges

The project revealed that mothers found it difficult or even impossible to distinguish between different issues affecting their and their child's wellbeing such as discrimination or public transport. These issues were considered to be all relating and intersecting with one another in defining their lives.

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It is sort of like a circle, things that we are doing on a daily basis. For example, going to R. (hospital) and having to take a taxi, having to meet grumpy people on the road who are not able to help you [...]. Because those are the things that we get to live in our daily lives.

(Group session with South African mothers)

The disability of their child was merely perceived as an additional challenge in life, on top of all the other existing disadvantageous factors. These compounded challenges led mothers to experience such profound psychological stress that at the start of our project they could not see any possibilities for change in their complex lives.

While the wellbeing of mothers and their children could be perceived as a personal experience, we argue, based on our results, that wellbeing is invariably a product of both the mother/child dyad and the “relations” they have with the external environment which construct the challenging reality of taking care of a disabled child (8). This is what is called a ‘relational reality’ in which not only personal aspects but also external disadvantages such as socio-cultural prejudices, gender norms, the poor provision of basic medical and disability services, poor living conditions, and underperforming state institutions weave mothers’ caregiving of a disabled child and their wellbeing (9).

Solitary caregiving - Adapting to a challenging relational reality

Interviews, group discussions, and workshops with mothers highlighted how they adapt to their daily constraints when caring for a disabled child. The omnipresence of discrimination, violence, and abuse not only towards their child but also towards themselves is the main force that drives mothers into a 24/7 caring role completely on their own.

A Zimbabwean 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”’

Their decision is simultaneously influenced by their personal, socio-cultural, and religious norms and beliefs on ‘good’ motherhood and caregiving. These drive them to care on their own and protect their child from the detrimental and unsafe context.

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We choose to live differently than others. We create a small world of our own. Just us and our child. We keep quiet, ignore others, and live our lives in our home.

(Nomthandazo, South African mother)

However, such a solitary preference further decreases their quality of life in terms of (gaining) income, basic needs provision, and personal health. Causing women and their children to be even more marginalized and consequently render them virtually invisible to policymakers and institutions (10).

TOWARDS A SHARED RESPONSIBILITY FOR DISABILITY AND CARE INCLUSIVE DEVELOPMENT

Our participatory project revealed the importance of a relational understanding of the deep-rooted forces that urge women into adopting a solitary form of caregiving. We argue that only through a relational approach on disability and caregiving in poverty it is possible to develop sustainable public interventions towards disability and care inclusive development.

A relational understanding of these women's lives takes the onus of care and wellbeing from the individual mothers. Instead, a shared responsibility of care emerges as it underlines the influence of all "relations" for wellbeing. A shared responsibility between peers, family, civil society, and the state can break the forced solitary nature of caregiving and generate better life outcomes for mothers and their children. This collective character can result in changes at the local level, without denying any socio-cultural, political or even global factors that influence women's decisions when caring for a disabled child.

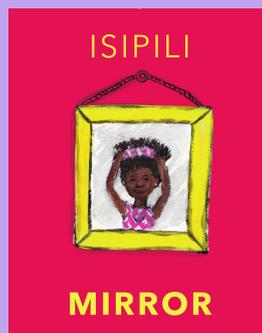
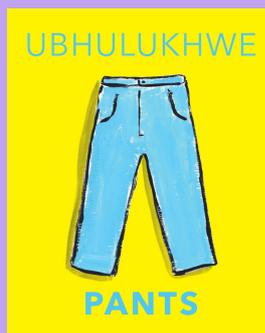
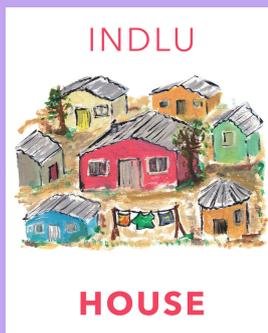
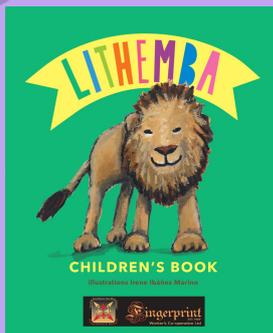
A first step to fully develop a shared responsibility towards disability and care is to generate collective awareness on the complex and compounded day-to-day struggles which mothers of disabled children face. Our participatory research sets a great example in which mothers co-created education and information materials on disability and care. Such materials could be further developed in ways to create broader societal awareness and conscientization. In addition, we argue three elements are crucial for shaping a shared responsibility for future disability and care inclusive development.

Eradicate the forces of stigma, abuse, and discrimination

First of all, our research shows that forces such as discrimination, violence, and abuse push mothers to solitary forms of caregiving. Eradicating these disadvantageous social and structural issues through a shared responsibility can set off a change in the mother's agency and, thereby, nourish their child's and their own well-being. Public interventions and programs can thus become more impactful by not only increasing access to services but also by aiming to eradicate the omnipresent negative forces of discrimination, violence and abuse when doing so.

Without eradicating these forces, mainstream public interventions on for example gender equality and care would probably fall flat. Mothers highly value their maternal role and would not let others care for their child as long as they suspect harmful practices. Likewise, solely investing in more (and more accessible) day-care services will probably not incite mothers to make use of them as they would still anticipate abuse. Instead, the compounded aspects of stigma, poverty, and disability should be addressed.

We argue that public interventions not only need to acknowledge and recognize the major influence of discrimination, violence and abuse, but also focus on eradicating it. Collective disability and care awareness raising as mentioned before with families, community members, public transport drivers and (para) medical professionals could be a first step. Similarly, public education campaigns on the rights of disabled people and the need for social equality, unity and respect are vital to alter the highly constraining context for mothers. Moreover, more interventional and intensive practices, such as providing for high quality, abuse-free day-care and education facilities, and inclusive public transport are equally important.



Box 2. Pages of educational book created by South African mothers

Reach out for the marginalized

The solitary care approach mothers choose when caring for a disabled child living in poverty hampers the possibilities for governmental and civil society actors to reach out to them. Likewise, it reduces the mothers' inclination to seek support and services themselves.

Public interventions in the lives of these women and their children should therefore be based on a critical awareness of the intersecting challenges women face and the internal notions of 'good' motherhood which influence them into not seeking or accepting any support. Translating this to practice means that institutions and organizations should make conscious efforts to establish contact with mothers 'outside' of the mainstream services.

Many organizations and programs, for example, rely on medical centre waiting rooms or day-care attendance lists to connect with mothers and include them in their services. However, mothers who opt for a solitary life remain to be excluded. Such mainstream services can indeed provide a first entry point. Yet, other approaches such as word-of-mouth and snowballing are indispensable to enable a more inclusive process. Herewith allowing to reach out to the highly vulnerable group of 'invisible' mothers and children for participation in interventions and programs.

Foster caring relations and emotional healing

Finally, when reaching out to such a marginalized and highly vulnerable group, institutions and organizations should be critically aware of the severity of the psychological stress mothers experience and therefore the expected impact of breaking their isolation.

A gradual and timely approach in which there is room for emotional healing proved to be a prerequisite for motivation, participation, and eventually for change to occur in our research. Emotional healing is herein understood as "any strategy, process or activity that improves the psychological health of individuals". We do not suggest that future interventions should focus solely on healing but rather connect a process of emotional healing to a collective approach to social change and wellbeing. In such a process, institutions and organizations must first make provision for qualified, trustworthy professionals to facilitate a process of collective emotional healing among mothers, before attempting to integrate them into existing or newly developed programs. Time and costs allowed an "extended" version of Participatory Action Research can play a leading role in providing this crucial space.

RECOMMENDATIONS

- **A relational understanding of the deep-rooted forces that urge mothers of disabled children into solitary caregiving is crucial for future disability and care inclusive development.**
- **Broad societal awareness needs to be generated about the intersecting challenges these women face- such as disability, stigma, poverty - and their implications.**
- **A shared responsibility among peers, family, civil society, and the state for disability and care is essential for holistic interventions which break the forced solitary nature of caregiving and generate better life outcomes for mothers and their children.**
- **Government and civil society actors need to acknowledge, recognize and aim to eradicate the omnipresence of discrimination, violence and abuse in their disability and care efforts.**
- **Within interventions, conscious efforts should be made to establish contact with mothers 'outside' of mainstream services. Approaches such as word-of-mouth and snowballing could enable a more inclusive process and avoid leaving out those mothers invisible to the system.**

This policy brief synthesizes research findings, analysis and policy recommendations on disability caregiving in poverty in an accessible format. This brief is based on research and written by Dr Elise van der Mark, Athena Institute, Vrije Universiteit Amsterdam, the Netherlands and co-written by Laura Pilz González (MSc). To see the full bibliography, visit www.elisevandermark.com. For further information, please email e.j.vander.mark@vu.nl.