Unrecognized Labour: Mothers Caring for Children Living with Disabilities in Igunga District, Tanzania

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List of Acronyms

CMT	Council Management team
CRPD	Convention on the Rights of Persons with Disabilities
DED	District Executive Director
FGD	Focus Group Discussion
ISS	International Institute of Social Studies
LCA	Law of the Child Act
MP	Member of Parliament
NBS	National Bureau of Statistics
NGOs	Non-Governmental Organisations
OHCHR	Office of the High Commissioner for Human Rights
PWDA	Persons with Disability Act
SDGs	Sustainable Development Goal
SWO	Social Welfare Officer
TASAF	Tanzania Social Action Fund
URT	United Republic of Tanzania

Abstract

This qualitative study explored the daily experiences, challenges, and support needs of mothers caring for children with disabilities in Igunga District, Tanzania. The study examined mothers ' daily caregiving roles through in-depth interviews and focus group discussions with mothers, community members, and social welfare officers. The findings revealed that mothers face burdens due to norms assigning them a primary care responsibility, and a lack of family and community support. Caring for children with extra needs limits their livelihoods and subjects them to stigma and neglect which prevents them from participating in work or other activities.

Mothers struggle to access services and require economic empowerment, recognition of their contributions, and inclusive support networks. The study concluded with the need to address social and gender injustices and promote mothers' well-being to achieve equitable outcomes as the study is dedicated to centering women's voices. Moreover, by using Frasers's modal of justice the study addresses an urgent collective intervention of recognition and redistribution to support mothers caring for children living with disabilities.

Relevance to the Development Studies

When I look at the lens of Human Rights, Gender, and conflict studies I come across the global debate on care work as an important focus of recent feminist arguments on the recognition of care work, and revaluing caregiving activities as part of social and gender justice outcomes (Nedelsky,2023; Harcourt,2023, p.3). A study conducted in India, Tanzania, Nepal, and Rwanda, indicates child care and elder care work are among the un-compensated responsibilities undertaken by women (Chopra, 2021). In Tanzania, care work is also overlooked (McNally, & Mannan, 2013). My research contributes to the current debate by presenting the everyday experiences of women who provide care for children living with disabilities. Based on the understanding of women's daily life in care, the study informs policies and programs for inclusive development aiming to improve the mother's well-being to achieve gender justice.

Keywords: Mothers, Disability, Children living with disabilities, Caregiving, Social Justice, and Gender Justice.

Chapter 1: Background of the study

1.1 Introduction

This research is grounded in my professional work experience and an interest in the advanced social welfare systems in Tanzania, specifically for underserved populations, in line with my passion from a young age. Since 2014 I have worked with vulnerable groups including children, women, the elderly, and people living with disabilities. Currently, under the Ministry of Community Development, Gender, Women, Children, and Special Groups. To fulfil my role as a social welfare Officer I am working to promote their rights and address their needs. In this period, I have heard, observed, advised, served, and attended diverse of these groups

Compared to other key groups I served; I realized that children living with disabilities require special attention and care. From what I observed and learned in the Igunga District; cultural norms mainly assign women the responsibility of taking care of the family including other duties. A woman is responsible for doing all the household tasks such as collecting firewood for cooking, fetching water, grinding food in the machine, cooking, feeding the children, and washing while having the responsibility of serving her husband. The existing cultural system has given a man the authority to make decisions while the woman receives and obeys the decisions made.

For families with children living with disabilities, this disproportionate burden presents challenges due to intensive care needs.

As a social welfare, I agree that these children deserve care, but why the mother's care alone without being acknowledged is my concern. I have seen women struggling alone to access the health services and treatment of their children, many of them have been abandoned by men just because they have a child living with a disability and the system of polygamy is a common thing in the area. Due to the persisting cultural norm that a man is always a decision maker and needs to be respected by a woman, I experienced that, if a father abandons a disabled child or the family, it seems normal and requires family mediation and reconciliation, though if a mother abandons the child, it is the opposite and it is not normal, immoral behavior and too much judgmental for a woman. Also, in this society, there are still negative attitudes about disability that create a burden in care, believing that having a child with a disability is a sin, a mistake, and a curse. In this situation, if a woman gives birth to a disabled child passes lots of judgmental attributes, and is pointed out as part of the mistake in the family, which leads to stigma, social isolation, and guilt for the mother.

Along with the stigma, there are magical beliefs and misconceptions against persons with albinism that their organs are the source of luck and wealth. In Tanzania, we still experience acts of brutal killing of people with albinism due to negative beliefs. In 2014, I participated in ensuring the accessibility of services and the rights of Suzana Masaga, a woman with albinism, who lived in Igunga, she was attacked and her hand was cut off due to negative beliefs. Again, this year, in June 2024, Asimwe Novath, a two-year-old, female child, and resident of Muleba was brutally killed and her limbs were cut off. In all of these situations, because women are primary caregivers, they exercise care under stigma, fear, and isolation. Despite the government, civil societies, and organizations intervening through awareness programs still, there is little understanding of mothers caring for children living with disabilities

With efforts to bring equality and strengthen the social welfare systems, the Tanzanian government has tried to involve special groups in social and economic empowerment strategies. Under the local government finance Act, (2019,290, 37A (4)), in line with the rules for providing loans to groups of women, youth, and people living with disabilities. According to the Act, 10% of the local income is allocated to these groups. Following the procedure, women and people with disabilities are among the groups, allowed to get loans through local governments. Some of the qualifications of getting a loan are; being above 18 years old, being mentally fit, national identity, and being in a group registered and recognized to get a loan. However, due to the conditions for obtaining a loan (Rule 6. a-f), children with disabilities under the age of 18 and with mental disabilities cannot get a loan but rather continue depending on their primary caregivers

Moreover, it is rare for women who raise children living with disabilities to ask for a loan despite the education and awareness given. These mothers fear being sued for not returning the money because of their limited time to engage with the groups, fulfill the groups' goals, attend the house chores, and perform caregiving roles. Thus, due to the difficult procedures, rules, and regulations to access these loans, disabled children and their mothers are not benefiting. Therefore, understanding the daily life of these groups is important for an inclusive approach.

As a social welfare officer who works to promote and protect women's and children's rights, I understand and promote the parental responsibility of care for one's children according to the National Law of Child Act (URT,2009 Rev.2019). Yet, I wish to hear and learn more from the experiences of mothers who provide care for children living with disabilities and seek a policy response on favorable opportunities in caregiving.

1.2 Beyond their struggle, a call for action

Igunga district was officially established on 20 July 1975. The district has one council established in 1984, and one small town authority established in 2009. The district has four divisions of authority; Igunga, Igurubi, Manonga, and Simbo. The governing authority in the area starts from the village level with community leaders to the district level. These systems help the community access services and reports (District Profile,2024). However, depending on the issue, the community still has traditional systems of responding to issues or problems at the family and household levels. Politically, the district has two members of parliament from Igunga and Manonga constituencies who represent community voices including marginalized groups

The networking is diverse with different tribes, but the dominant tribes are Sukuma, Nyiramba, and Nyamwezi without ethnic differences. In this society, I observed that at the family level, a man deserves priority compared to female children and women, there is a cultural practice where women cook and prepare food first for men in the family, and then women eat after serving the man and assuring that all men in the family are satisfied. These cultural beliefs, norms, and values continue to position a man as the head of the family and a decision-maker while women ensure family care. Religious practices and beliefs are personal whereby both non-religious and religious groups are found however, Christians and Muslims are the dominant religions in the area and play a big role in challenging negative practices and beliefs and helping groups in need.

To ensure the provision of health services and primary health care, the district has 78 health service centers and 2 hospitals owned by the government, religious organizations, and private institutions. According to the available National Health Policy (URT 2007, pp.28-29), among the special groups that access free health services persons with disabilities are not mentioned. The groups intended are children under five years old, pregnant women, and elderly people over 60 years old. Moreover, the district has free access to primary and secondary education. The district has 145 primary and 38 secondary schools, while it lacks schools for children with disabilities, and is also limited to welfare institutions for persons with disabilities.

Furthermore, community services and empowerment are part of the district strategy. It provides loans to Women, Youth, and people living with disabilities as per the financial law of the local government authorities chapter 290 and its regulations. Likewise, the district coordinates social welfare services to the special groups in the sections of; children in conflict with the law, the elderly, and people with disabilities, and the family child care, and development section

As a social welfare officer in Igunga district, I am concerned with researching mothers who care for children living with disabilities on how they manage their caregiving roles in the situation of limited support. My research will seek out the challenges mothers of children with disabilities face, to understand their daily lives and struggles.

Due to the limited support systems mothers caring for children with disability are vulnerable to social interaction and networking. I have seen how isolated and overwhelmed these mothers are as they dedicate themselves to caring for their children alone. Not only do they have to navigate the difficulties of their children's conditions and needs, but they also have to struggle with poverty, lack of access to services, and negative social attitudes. As a result, the needs of these mothers often remained not possible. I believe that no mother should have to struggle alone. No child deserving of love and care should suffer due to a lack of support and understanding from the community.

I want to understand the barriers they face in caring for their children, the particular needs of their lives and livelihoods, and what kind of support systems could help ease their struggles. I wish to let these mothers share their thoughts, challenges, and needs. I believe bringing their experiences could help to foster more responsiveness, and awareness to facilitate necessary change. In doing so, my goal is to empower mothers and enable support for their important caregiving work, which is often taken for granted. As a social welfare officer, I understand that all children deserve to grow up with dignity, and all mothers deserve to give their children the best without distressing.

Chapter 2 Disability and Caregiving

2.1 Introduction

This chapter focuses on understanding disability, caregiving, and the daily experiences of mothers caring for children living with disabilities in Igunga District, Tanzania. In this chapter mothers caring for children with disability are central focused. Also, the case studies will be discussed to provide a brief picture of the mother's life experiences in the caregiving domain that expose them to stigma and lack of assistance from partners and the community. Moreover, the chapter briefly explains a conceptual framework centered around social justice and intersectional feminist perspectives as an analysis to inform discussion around improving policies, programs, and equitable outcomes for mothers caring for children living with disabilities.

2.2 Disability and caregiving in context

Disability and caregiving are deeply intertwined social issues in the Tanzanian setting. According to the 2022 national census,13.6% of the total population lives with disabilities, including 0.7% of the children (NBS,2024). Culturally the duty of care for these children falls on mothers, who are expected to provide physical, emotional, and practical support (Reimer-Kirkham, et al,2020; McNally and Mannan,2013, p.2) However, the burdens, and challenges these mothers face are rarely acknowledged or addressed in policies and interventions.

The existing studies have highlighted the significant social, economic, and psychological impacts of disability and caregiving on mothers in Tanzania (Likumbo and Kryiacos,2021; Ambikile and Outwater,2012, p.8). Mothers often face social isolation, financial constraints, and physical and mental health issues due to the constant demand for caregiving. Moreover, the gendered nature of care work further exacerbates inequalities as women's contributions are undervalued and their needs are often overlooked.

While Tanzania has made steps in recognizing the rights of people living with disabilities through the ratification of the United Convention on the Rights of People living with Disabilities (UNRPD,2006) and the enactment of the National Persons with Disability Act (URT,2010), the need and experience of their primary caregivers remain marginalized. The ongoing human rights discourses highlight stigma and dominant structures that continue to marginalize people with disabilities and their families (Ned, 2022, pp.494-495). The SDGs 2030 target to leave no one behind (Abualghaib et al,2019, p.2) while, home care is becoming the standard care for children with complicated needs over institutional care (McCann, 2021). In the situation of unrecognizing women's labor mothers are more likely to continue overburdened without financial, social, and cultural freedom when implementing home care activities.

The social welfare system in Tanzania promotes children's rights through the child protection system which identifies the family as the best place for children's growth and well-being. Through the Law of the Child Act, the local government authorities have been given a mandate to ensure the implementation of the child protection system (URT,2009 Rev, 2019, sect. 54). As a social welfare officer I understand that excluding the child from the family setting is the final resolution when working for the best interest of the child. However, in the situation of little attention to mothers caring for children with disabilities, most of them raise the concern of linking their children to children's home centers not because they don't love their children but because of the limited support they get. This research needs to address these gaps by exploring the daily realities, challenges, and possibilities of support, to achieve inclusive justice for mothers caring for children living with disabilities.

Why I am concerned?

As a social welfare officer, in performing my duties, I met with three women who were caring for children living with disabilities. Their lives have been repeating to me to reflect on all the other women like them, whom I have worked with to understand better their situation of caring for children living with disabilities. In my study I want to know what is happening to them, their paths through their daily living, and what could be better for their well-being. The fact that I am here Studying at ISS learning more about human rights, gender justice, and development. Also having a chance to reflect back on what is happening in my community regarding the issue of mothers caring for children living with disabilities, I also wish to understand what I could do better as a social welfare officer.

The First Case

One day in 2019, was not a working day. While at home I received a phone call from the District Commissioner who is the president's representative at the district level. The issue was about a mother of a 3-week-old baby with albinism, in need of emergency service due to negative beliefs and inhuman practices toward people with albinism. After meeting with her at the office she explained that she wanted me to take care of her child because of the security of her family and her child. This woman had separated from her husband immediately after giving birth to that child, and she was left with a baby and other children who depended on her. She did not want to care for the child due to the stigma of albinism. After receiving psychosocial support, she agreed to take care of the child. Despite the care plan prepared, I was left uncertain if she would manage off, as there was no childcare center in the district. The child is in good condition under the care of her mother and continues attending the skin clinic services at the hospital.

The Second Case

In 2020 a mother and her child from Bukoko ward were referred to my office. The child was without arms and legs. She was intelligent, able to communicate, curious, and funny. The concern of the mother was the lack of support from the father. She was looking for home care for her child, and she reported that she could no longer take care of the child because of being dependent on her parents and brothers since the child was born. She was planning to find a job, she needed to leave the child behind. We could not find the child's father, but we managed to conduct a meeting with the family, including her brothers. The mother left the child in the care of her uncle, even if we advised the mother to stay with the child. The ongoing follow-up is under my fellow social welfare officers to understand the well-being of the mothers after leaving the child.

The Third Case

Another case from the Ntobo ward was about a child with disabilities who was left alone without monitoring and care. I met the mother and her two children. One child had multiple mental and physical disabilities. The mother explained that it happened when the child was two years old when he lost his body function, but before that, he was a normal child. The other child was a primary school student. Their father had left them for another wife. The mother said, “It is painful to leave my child alone but he is too heavy to carry”. As he could not communicate, walk, and talk, it was very difficult to get someone to care for him. The child was given a wheelchair from the social welfare office to reduce the carrying burden.

The Invisible Burden

My experience from the above cases reflects that providing services and support to mothers caring for children with disabilities is a complex task, and understanding how they cope with their caregiving is an important step for an equitable society, however, still they are unknown and even ignored. These cases show the way heavy and sole responsibilities force mothers into the dilemma of abandoning their children due to a lack of support and resources. Moreover, the cases highlight the need for acknowledgment and appreciation of mothers.

For example; the first case shows the great stigma and fears that mothers of children with disability particularly children with albinism face as a reason for mothers to give up their newborns due to social-cultural concerns. Despite receiving psychological and counselling support, the long-term uncertainty on how she will manage caring for her child independently is concerning, especially in an unsecured environment, and fears without support.

The second case shows the great burden placed on mothers, who are forced to leave their children living with disabilities in the care of another family member to seek employment and financial support. Considering that the father ran away and the mother had to rely on her parents indicates the limited support systems to help these mothers. Moreover, the third case highlights the painful situations where the mothers are pressed to leave their children with severe disabilities alone without close care for them due to physical demands and lack of support. The mother's words, "It is painful to leave my child alone but he is too heavy to carry", represent the pain of mothers with impossible choices for their lives and their children. Despite a wheelchair provided, it makes us imagine the comprehensive support and accessible resources.

Across these three cases, the subject arises: Without support from their husband, families, the community, or the government systems, mothers are placed in unequal responsibility of providing care for their children living with disabilities. In this way, mothers continue to perform the roles alone, under stigma, isolation, and financial challenges with physical and emotional pain. Reflecting on these cases I see the urgent need for a comprehensive understanding of the situation of mothers in caregiving to children living with disabilities.

2.3 Statement of the problem

Providing care for a child living with a disability is laden with challenges that go beyond the norms of parenting, as supported by Clari et al (2022, p. 2-3) on the perceived family functioning among the caregivers. Caregiving is seen as primarily a female task in most of the Tanzanian cultures (Reimer-Kirkham, et al,2020). In Tanzania, caregiving responsibilities are assumed to be taken up by the mother as part of their gender role in the family and community. Because of this, women can become vulnerable economically and socially because caring duties are frequently performed unpaid and without recognition (Lawrie, 2018). Because raising a child living with a disability requires more time, women are limited to engaging with other economic struggles as a result of financial barriers (Castellani et al,2022, p.484). Castellani and colleagues in understanding the challenges of developmental disabilities in rural Tanzania, found the decline of occupational earnings to parents in care for children with developmental disabilities which creates a demand for comprehensive support and social protection in response to a just society.

Significantly, caregiving of disabled children has direct implications for mothers' well-being (Cantero-Garlito et al,2020, p.1). Mothers who care for children living with disabilities face unique challenges and difficulties in both developing and developed countries. A study conducted in Norway finds that they experience higher levels of physical health issues, and psychological distress compared to mothers of children without disabilities as a result of social and economic threats (Østerud et al,2024,5; Brekke and Alecu,2023, p.4), while in Malawi disability leads to high social isolation and marital discrimination against mothers who gives birth and care for children with disabilities. Due to this, the experience of mothers excluding from their families and husbands continues as a normal thing in developing countries as exposed by Likumbo, et al (2021, p.5).

Women in the Igunga district encounter social, economic, and cultural constraints to access opportunities, resources, and support networks. Their struggles and contributions are often not seen or valued, but rather perpetuate the vulnerabilities of these mothers and their children leading to societal inequities. Even if it is estimated that 9% of unpaid Tanzanian carers provide service for persons living with disabilities (McNally & Mannan, 2013), still caring role has uncountable value.

2.4 Research Gap

Women's involvement in caring activities is a culturally expected role in the Sukuma and Nyamwezi cultures. Women are seen as the primary providers of food, and caregivers of the whole family with multiple roles. As Chung and colleagues revealed, regarding their caregiving burden, they still have to participate in other farming activities to meet other responsibilities (Chung, et al 2019, p.1545). However, despite the partial programs that aim for women’s equality and to reduce women's burden of caregiving the national policies and interventions in Tanzania are failing.

Several study findings show that mothers are the primary caregivers for individuals with disabilities (Sakwape, et al.,2023; Brekke & Alecu ,2023, p.2; Kuper, et al.,2016; McNally & Mannan, 2013; & Mbwilo,2010) but there is a limited understanding of the daily life experiences, challenges, and specific needs of mothers as the primary caregivers to children living with disabilities, in rural Tanzania from a social justice lens. My research focuses on filling this gap by examining the daily life experience, challenges, and needs of mothers caring for children with disabilities grounded in the justice perspectives of the mothers who exercise care for children living with disabilities.

2.5 Research Objective

The overarching objective of this study is to explore and analyze the daily life experiences, challenges, and specific needs of mothers caring for children living with disabilities focusing on enriching social justice and gender justice in Igunga District, Tanzania. It also aims to determine how the perspectives of community members and government social welfare officers in the district influence the experiences of these mothers.

2.6 Research Question

How do mothers of children living with disabilities navigate the daily caregiving role and responsibilities for their children?

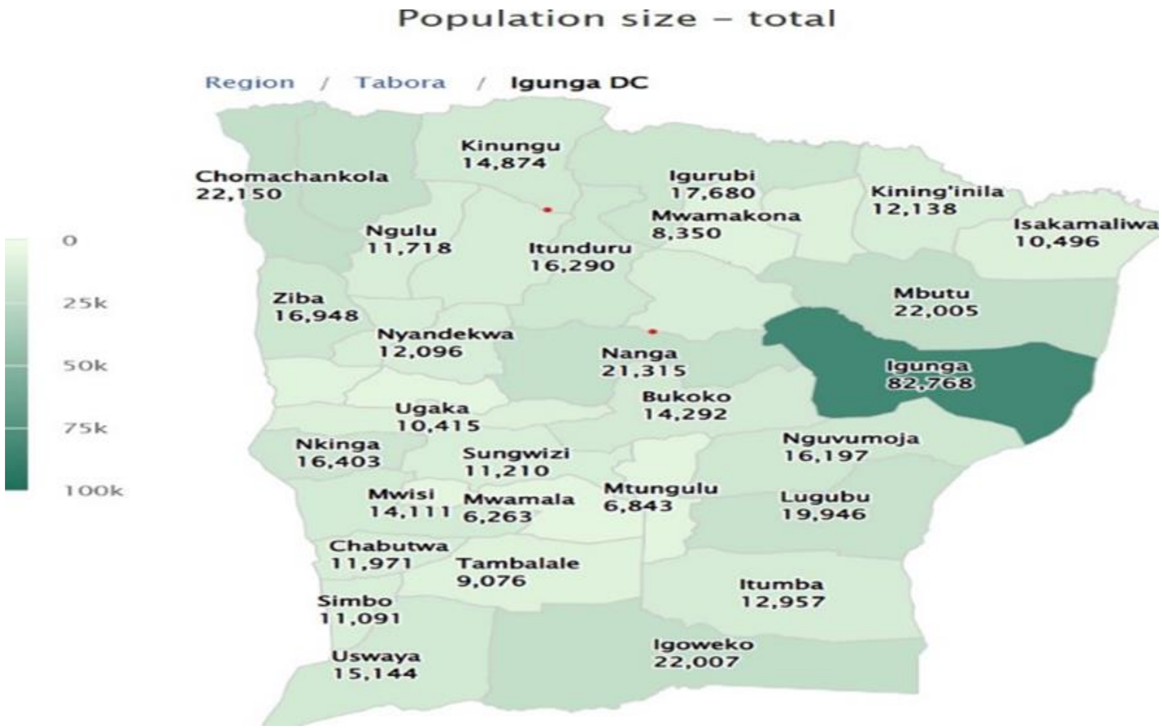
2.6.1 Sub-questions

a. What are the particular challenges and barriers mothers caring for children living with disabilities face in raising their children?
b. What are the unique needs and support systems that impact the well-being and livelihood of mothers caring for children with disabilities?
c. How can the study findings contribute to addressing the experience of these mothers caring for children living with to promote more equitable and inclusive outcomes?

2.7 The scope and profile of the study area

The Igunga district in Tanzania's Tabora region will be the site of this research. The study targets the mothers who are primary caregivers of children with disabilities in the district. It focuses on the Igunga district in particular, and participants are mothers who provide daily care for children living with disabilities, community members, and social welfare officers were questioned to obtain diverse perspectives regarding the issue. The reason for choosing the area is because it is my workplace, also I have lived for 10 years in this area which I take as an advantage. The district includes geographic and socioeconomic backgrounds, and semi-arid settlements that make up the area descriptive. Likewise, the district is predominantly a rural area with a significant population of 597,226 female-303,438 & Male-293,788 based on the 2022 National Census (DED's office & NBS,2023). The administrative area is in 4 divisions, including 35 wards,119 villages, and 754 hamlets with the total households 88,291. Moreover, the district is dominated by the Nyamwezi and Sukuma tribes characterized by its unique social-cultural context which is influenced by cultural norms, beliefs, and practices that affect, gender roles and care responsibilities.

The main economic activity is subsistence farming, including agriculture, livestock keeping, and small-scale trading. The district covers 6,788 square kilometers and accounts for 8.9% of the Tabora region. Its vegetation cover varies from forest and woodland to bush and bare land, with a decreasing trend of forest and woodland. Water resources show slight depletion, with plain land with black soil and three seasonal rivers leading to gender roles and burdens. The district is semi-arid with annual rainfall between 500-700mm and a mean temperature of 250-300C. Regarding gender burden, women spent over 6 hours searching for firewood which accounts for 88% of domestic energy, 78% of households are within 400m of water supply and accessibility while 98%are farther away (District Profile, 2024).



Map 1: Igunga district profile (NBS,2023), source https://sensa.nbs.go.tz/

2.8 Conceptual Framework

The conceptual framework of this study is grounded in a social justice framework guided by a feminist perspective on care and gender justice. It also draws on intersectional feminist perspectives on the ways gender, care, and disability meet to create the vulnerability of women caring for children living with disabilities.

Rawls explained social justice as the fair and just relation between the individual and society that, the clear and agreed terms of the distribution of wealth, opportunities for personal activity, and social privileges can measure (Rawls, 1999, p. 4). From his perspective, we see how social justice demands fair and equal treatment to all members of society, with special attention given to those most disadvantaged or marginalized (p.54). Like Rawls, Fraser addresses social justice as the equitable distribution of material resources in society especially in the childbearing field (Fraser,2013, pp-22-24), adding recognition that involves the cultural status, identities, and contributions of marginalized social groups (Fraser, 2007, p.26). To Fraser a just society requires attending to redistribution and recognition as neither alone is sufficient to remedy injustice.

We also expand to know that social justice involves challenging any kind of injustice and promoting inclusion. Often, looking at culture and traditions through a diverse lens, misrecognition, individualism, and oppression are closely related to unequal and exploitative social systems under capitalism (Mladenov,2016, pp.1230-1232). Unequal structures inform the social justice framework to promote equality and seek fair and equal distribution of socioeconomic resources as well as responsibility. I have used this framework to understand and analyze the accessibility of opportunities, services, and resource distribution regarding mothers caring for children living with disability and its outcome for an equitable society.

From a feminist perspective, caregiving is addressed as socially necessary labor, essential for survival and stimulating social-economic relationships (Harcourt,2023, p3), however is unseen and taken for granted. I see Feminist thinking as central to interpreting and analyzing the established policies and programs to understand women's position in a certain context. Bringing gender justice in care requires the recognition of care activities and fair distribution of resources and care responsibilities (Fraser 1998, p.9). Moreover, structural support and recognition of the caregiving burden of mothers caring for children with disabilities have a significant outcome toward misrecognition and gender justice (Suiter and Heflinger (2011, pp.196-197)

I find the two dimensions of justice; redistribution and recognition by Fraser, provide a way to understand the life of mothers caring for children living with disabilities in Igunga District. The culturally assigned role of mothers as primary caregivers coupled with stigma, and lack of support has created inequalities in the intersection of gender, disability, and caregiving. Moreover, I also link these dimensions with the findings that emerge from socioeconomic constraints and the misrecognition of mothers due to patriarchal structures that subject mothers to vulnerability and make to understand caregiving to children with disabilities as an issue of social and gender justice.

2.9 The Study's Guiding Concepts

Caregiving; Here the study examines how cultural norms and power dynamics situate caregiving as a primary female responsibility, and the implications for a mother's well-being. The analysis will focus on the ways various forms of oppression, such as gender, disability, care, and cultural marginalization intersect to affect women.

Redistribution and recognition; Achieving gender justice requires both redistribution and recognition, and one alone cannot be adequate (Fraser,1998, pp.2-3). The study examined how socioeconomic and cultural structures shape the daily life experiences of mothers caring for children living with disabilities in Igunga District, Tanzania.

Needs and Challenges; Identifying the specific demands, barriers, and support systems that shape the daily lives of mothers caring for children living with disabilities.

Social justice and gender justice outcome.; Here, I focus on policies, programs, and relevant interventions to address the inequalities faced by mothers of children with disabilities in promoting more equitable inclusive outcomes.

Chapter 3 : Research Methodology

3.1 Introduction

In this research, I employed a qualitative methodology in gathering primary data from the Igunga district, Tanzania. According to Hesse-Biber (2014), the qualitative method is well-suited to capture the rich contextual experiences and perspectives of marginalized groups. Also, Kvale and Brinkmann (2009, p.29) said the qualitative research method is important when exploring participant's thoughts on a subject to understand the central claim in a normal conversation. The above arguments make me engage the qualitative method as a suitable approach to understand my participants' responses very well when listening and interpreting their experiences to draw meanings.

To get the stories, and experiences of mothers caring for children living with disabilities. I also employed a qualitative feminist methodology to get a comprehensive understanding of the situations of the women who are the primary caregivers of children living with disabilities. I first, focused on the stories of the mothers and also investigated about the perspectives of some community members to obtain diverse experiences and information about the lives of these mothers who are taking care of children living with disabilities. Moreover, I employed the qualitative feminist methodology to enable me to understand the mother's real-life experiences without my personal biases. To get the data, I used semi-structured tools such as in-depth interviews, and focus group discussion methods. My interview questions were framed in the form of an interview guide to create free conversation and maintain the consistency of the participants' conversation as attached in the appendix of my research. A maximum of 12 open-ended questions followed by probes on each question were asked in order to obtain wider information from the participants during the interview and focus group discussions. Mostly, the time used for each interview was 50 to 60 minutes for an individual respondent and a maximum of 3 hours for the Focus group discussion. However, due to the internet problems, I used up to 80 minutes for some of the interviews.

Furthermore, I employed an autoethnography approach by using my personal experience, also reflecting on three cases of mothers caring for children living with disabilities I encountered during my time in the office and community engagement. Thus, reflecting on my 10-year personal experiences as a social welfare officer in a government department who works closely with marginalized groups including those mothers in the community is important for this research. According to Chang (2016, p.26). Autoethnography extremely benefits from the idea that the self is an extension of the community rather than an autonomous one. Chang's argument led me to find this approach a relevant method to guide my professional experiences and reflections to compare with the other methods for an in-depth understanding and analysis.

3.2 Sampling and Data collection

The participants of the study were selected through purposeful sampling. The age requirement of participants was an adult age above 18 years, also I selected participants who are caring for children living with disabilities and some community members to get diverse and comprehensive information about the issue. Moreover, I was able to select the participants through close communication, and collaboration with the social welfare office in the district. I first communicated with DED's office by phone and sent the approved research ethics form from the International Institute of Social Studies (ISS) to help me organise the participants.

In addition, the process of gathering data took over one month from July to August 2024. Thus, in order to get data, I conducted a phone interview with ten mothers caring for children living with disabilities, and one focus group discussion with seven people (three male, and four female) without children living with disabilities. Knowing that my personal experience might have a bias I also interviewed with one social welfare officer to see if she could have a new experience on the mothers caring for children with disabilities. In this process, I involved a trained research assistant who helped to conduct the FGD, then the voice record was sent to me for data interpretation and analysis.

3.3 Positionality and Ethical Issues

When I was planning for the study my position as a long-time social welfare officer in that particular area for decades plus my relationship with the participants created fear for the study processes especially the data collection. However, contrary to that, it has significance during the data collection when people worried about participating in giving information related to disability due to the killing of a disabled child in a neighboring community. Nevertheless, being an insider helped me to build trust with the community members and the women to participate in my research.

As Roulston (2010, p.97) multiple degrees of consent might be needed depending on the research context. I realized that maintaining several consents was important in such a situation of community tension. I started disseminating an ethical research approval form from ISS through my research assistance to district authorities, local community authorities, and participants. I introduced my research assistant to DED's office and social welfare officers for cooperation. An informed consent form, which I translated in Swahili language was adhered to and signed by every participant. However, some participants asked not to mention their names, and I maintained their preferences throughout the study.

Summary of the Methodological Sampling

Table 1. Method and Total number of participants

Number	Method	Participants	Total Participants
1	In-depth interview	Mothers caring for children with disabilities	10
3	Focus group Discussion (FGD)	Community members	7
4	In-depth Interview	Social Welfare Officer.	1

Total 18 respondents.

Table 1: shows a summary of the number of participants involved in my research and the methods used to obtain information from them.

3.4 Data Analysis Dissemination and Report

The data interpretation and analysis were done through thematic analysis. Since I had a voice record of each interview and from the FGD. I identified the repeated themes from each interview through careful listening and taking notes. Then I grouped the themes based on my research questions. Lastly, I developed the main themes merged from all groups which I used for data analysis.

Dissemination and Report

Due to the concerns of study feedback from the participants. I am interested in disseminating the study findings to the Igunga DED's office, responsible ministries, policymakers, local community organizations, and networks, and also in organizing a community meeting with mothers of children with disabilities for feedback.

Chapter 4 : Data Presentation, Analysis, and Conclusion

4.1. Introduction

This chapter presents the key findings from the study's data collection and analysis. It is structured according to the main themes that emerged from participants' narratives regarding the daily experiences of mothers caring for children living with disabilities in Igunga District, Tanzania. The chapter begins by providing demographic information about the 18 participants involved in the study. This is followed by a thematic analysis of the data which is organized around the research objectives. The first section examines the caregiving roles undertaken by mothers and some reflections on the gendered nature of caregiving. The second explores the particular challenges and barriers they face in caring for their children living with disabilities. The third section analyzes mothers' articulated needs and the existing support systems. The last section presents insights into the daily lives of mothers and a description of the findings for equitable and inclusive outcomes.

Each theme is discussed drawing from interview and focus group data. Direct quotations from participants are included to privilege mothers' voices and lived experiences. The analysis also incorporates the researcher's observations and personal reflections from years of field experience working closely with these families. I aim to present a clear and comprehensive overview of the research process while maintaining participants' anonymity and respecting the sensitive nature of their shared realities.

4.2 Demographic Characteristics of the Participants

As stated above, the study involved a total number of 18 participants engaged in in-depth interviews and focus group discussions. The distribution of the respondents is indicated in Table 2 below.

Participant profile

Table 2 below shows the brief profile of the participants in my research.

Table 2:

Participant Number	Type	Gender	Age	Marriage status	No. children in the family	No. children with disabilities	Education	Work/Activity Apart from home caregiving.
PNT 1	Mother	Female	35	Deserting	3	1	Primary	Labourer in food vending
PNT 2	Mother	Female	46	Deserting	2	1	None	Street food vendor
PNT 3	Mother	Female	33	Married	4	1	Secondary	Small farming
PNT 4	Mother	Female	27	Deserting	4	1	primary	Fruit seller
PNT 5	Mother	Female	25	Deserting	3	1	primary	Food vendor
PNT 6	Mother	Female	48	Deserting	6	2	None	None
PNT7	Mother	Female	37	Deserting	4	1	primary	Labourer in Hotel.
PNT 8	Mother	Female	51	widower	2	1	primary	Fruit seller
PNT 9	Mother	Female	23	Single	2	1	primary	Food vendor
PNT 10	Mother	Female	30	Deserting	3	1	primary	Small farming
PNT 11	Community member	Female	28	married	4	0	secondary	Food vendor
PNT 12	Community member	Male	50	married	4	0	primary	Business
PNT 13	Community member	Male	54	married	3	0	Primary	Farming
PNT14	Community member	Male	55	married	6	0	secondary	Motorcycle mechanic
PNT15	Community member	Female	41	widow	2	0	primary	Small farming
PNT 16	Community member	Female	38	married	5	0	secondary	Grain seller
PNT17	Community member	Female	49	married	4	0	primary	Farming
PNT 18	Social welfare	Female	38	Married	1	0	Master degree.	Social worker

Table 2 above shows the participants involed in the study. These included mothers caring for children living with disabilities, and some community members who provided useful information on the situation of mothers caring for children living with disabilities. How they are treated in the community and the kind of recognition or help they get from the community and other institutions.

4.3 Gendered Nature of Caregiving: Some Reflections

The study was interested in understanding deeply the situation of mothers in caring for children living with disabilities. It was also interesting to hear from the participants' narratives on how caregiving has been shaped. The study found that the nature of caregiving seems to be completely women's domain and rooted in patriarchal control, A man has given over-power not only to women but also control to property and resources. I can remember very well about eight out of ten mothers I interviewed experienced a heavy burden of care after the desert of their husbands because they had to perform both their duties and men's responsibilities in taking care of the family without social, economic, and cultural power shifts.

From the mother's interview and FGD, the participants mentioned that parental responsibilities and traditional values attached to caregiving are gendered and the reason behind the stigma and discrimination of mothers caring for children living with disabilities. Regarding mothers being the primary caregivers, the experience from the community members shows that the Sukuma traditions, norms, and values do not allow men to participate in home activities such as cooking, washing dishes, and cleaning. These activities are mentioned as female work.

A mother of a child living with disabilities stated that,

> "Before the desert my husband, sometimes we attended the farm together, but when we got back home, he couldn't assist with anything, while everyone was looking at me, regarding that we have a disabled child who needed care, but cooking, and other housing chores was on me" (Interview,19th July 2024, Igunga)

A man, of 55 years old from the focus group discussion supported the discussion by saying,

> "All of us are witnesses and the men we are here. When have you seen a man cooking or bathing a child while his wife is there? Even if the child is wet, we call our wives, "Mama Fulani, come and look at your child", now take a picture of these mothers with helpless children" (FGD,27th July 2024, Igunga)

This statement was supported by all participants in the discussion, meaning that male-dominated behaviors are strongly rooted and usual in this community.

Furthermore, some participants stated caregiving as a shared parental responsibility by defining and describing the assigned responsibilities of a mother and father in child-rearing. Hearing from the mother's voice, the available traditional values of shared parental responsibilities do not function equally because when a mother has a child living with disabilities and men diverge from their responsibilities, no one questions. The father was mentioned to be the top of the family, the decision maker, and the breadwinner making sure of the availability of food, money, and other family needs. While a mother ensures home caregiving activities, and nurturing children into the acceptable community values. A woman, of 49 years in the focus group discussion stated

> "Culturally like other communities in Tanzania, here in Igunga, the father, even if he is present, is not involved in any activities of taking care of the child, the responsibility is for the mother and she is a guardian of the family. After giving birth to the child, we mothers are the ones to develop an attachment with compassion for raising children, while fathers don't care about the attachment, they care about being head of the family, finding money, and being respected" (FGD,27th July 2024, Igunga)

On the same issue, during the in-depth interview, a mother stated,

> "The problem is that my husband has left his responsibility to me, which is not fair, If I had to perform my only role of taking care of children as a mother while he provides food and family needs it wouldn't be a problem, but right now I am a father and a mother and no one is asking, even though I reported the issue to my father-in-law but nothing has changed" (Interview,17th July 2024, Igunga)

Definitely, hearing the stories led me to reflect on the three cases where I experienced an ethical dilemma and judged a mother who wanted to leave her child with me. I reflect back on the day when the community members reported injustice towards a child living with disabilities by finger-pointing a mother who left him alone. I now realize that behind the difficult decisions a woman makes against her child's life, there are gender forces and the dominant patriarchal thinking and practices that put huge pressure on her.

Similar to the participants, during my time in community involvement and office work I observed societal norms and values that reproduce gendered beliefs to position a woman as a primary and sole caregiver of children living with disabilities whether by choice or by compulsion. Concerning the matrimonial and neglect cases, I have seen the negative perceptions behind the traditional roles and norms which makes it difficult to imagine how a woman copes in this gendered situation. For instance; if a father in the house participates in home activities, the community defines that he is bewitched by his wife in order to take control over him and finger-pointed as a laissez-fair family. This means a family where a father in the house has no power to control or speak on behalf of the family and any family member can do what he/she likes. Here we can see the way gendered nature oppresses women and the ways mothers are forced to endure the hardship of providing care alone to avoid negative perceptions towards them and their families, the same situation found in the study of challenging the hidden oppression (Homes,2002)

During the interview, my tears welled up when I heard a woman caring for children with disabilities saying,

> "I have to stay, if it is death then I will have to die with my child because she is my blood" (Interview,17th July 2024, Igunga)

Listening to the above words from a mother I felt very hurt and started to consider helping. Suddenly I found myself in an ethical dilemma as a researcher, thinking that just talking to such kind of a mother, and leaving her with the same problems was not appropriate. However, I reflected on Raina et al (2004, p.12) who emphasize that simply identifying problems is not enough, the meaningful change requires moving the experiential study to guide future action which is my goal.

It is interesting to understand these mothers as the focus of my study, however, hearing their stories creates a painful situation. The findings from the participants and reflection on three cases of the mothers show the existing gendered cultural norms around masculinity and feminine thinking (Connell,2020) shape how a mother and a father should be in a family. The system that defines and allows a man to provide for his family at the same time, allows a husband to abandon his wife and family, and run away from caring responsibilities. In this situation, mothers struggle to overcome the unshared financial responsibilities with the heavy burden of emotional costs of caregiving while physical and mental health problems arise due to persistent care work without appropriate support. Think about the below statement of a mother,

> "Mmmh, as a mother how can I run away and leave my child" (Interview,17th July 2024, Igunga)

This strong statement from a mother of a child living with disabilities reveals the mother's resilience, however, the patient of caregiving undertaken limits alternatives and decision-making for them when taking the role of caregiving alone.

Moreover, through listening to the participant's experiences I find that within the families gendered power imbalances normalize husbands not to participate in care responsibilities and it has been designed in a way that, is inherited from one generation to another. The participant's stories particularly mothers tell the ways cultural norms shaped them to be caregivers from a young age. This is also supported by a mother, of 28 years old, in the FGD saying,

> "Since I was young, I used to cook with my mom, and my brothers worked with my father. Until now my brother does not know how to cook because they were restricted and not

> allowed to participate in the kitchen activities and until today, in their families, their sons are not participating in home activities" (FGD,27th July 2024, Igunga)

Furthermore, reflecting on the three cases, and my long years of working experience. I notice the ways the gendered attitudes perpetuate the stigma and exclusion of mothers in caring for children living with disabilities. Frequently, as a duty bearer to children, mothers, and their parental rights, I have been struggling to resolve family conflict, matrimonial cases, and neglect issues that have always been attached to feminine and masculine thinking that shape male and female life in society (Connell,2020, p.68-69). Receiving cases, and tracking these fathers for mediation and maintenance, I realized that it is not easy to reconnect the family where the mother is positioned at weak decision-making power compared to men.

From my experience and what the participants of the study tell me, gender relationships are vital in ensuring care for children living with disabilities. When I reflect on Fraser's concept, I agree that it is a critical issue that needs to be looked at in recognition and allocation of resources in line with empowerment programs (Fraser,2007), about the rights and responsibilities in the field of care. However, it might sound difficult because in most cases men who are sitting in the office coordinating planning and budgeting, raised in male-dominated systems do not easily understand the situation of mothers.

Here I reflect on the first budget allocated in my district for the social welfare unit to serve the marginalized groups after long years of working under zero budget. It passed under the close follow-up of the late DED, Fatuma Omary Latu 2021, after she was appointed as a female District Executive Director. I remember the day I visited her in the office with my proposal for funds she told me to call her at any time so that she could make sure the budget was allocated by the Council Management Team (CMT), a response I never experienced before. I can say that because the previous eight years the DEDs were male. As a woman, she knew the position of women as marginalized due to gender power relations.

Similar to the family and community, I observed men have power over women, however, their power is to achieve respect from women, and not help mothers in caregiving. As a social welfare officer, I have seen different reactions to power over women; I am also assigned to mediate and resolve family conflicts and matrimonial cases. Among the cases I have attended, physical violence against women is prevailing especially when women question their husbands about family income and needs. I remember the case of a mother who was insulted and beaten frequently by her husband in Mbutu village. The husband left her to another wife because she had a disabled child. Demanding her child's rights she came to the social welfare office for mediation, lastly, the case was filed at the court. When the case was ongoing, I met one of the court officers who was hearing the case, and he spoke to me, I quoted "Your client, a mother was denying her child's rights by herself because she doesn't listen or respect to the husband". This sentence hurts me, even though the child's right was obtained.

Likewise, when I attended the community meetings and events, I saw men's voices are part of the conclusion on the decision made even if the issue concerns women, whereas women's ideas are often disregarded. All this shows the ways power is exercised in a gendered society. The fact that these men are raised in a gendered society by experiencing male domination, adds that they are not the primary caregivers to experience the direct burden of looking after children living with disabilities. Therefore, for men to think and prioritize mothers' needs becomes difficult.

Concluding to the above, the study findings show the ways the gendered nature of caregiving shapes the daily life of mothers caring for children living with disabilities. It also shows the regenerative gender bias that continues to create stigma, risk, and exclusion of women to social-economic life by mainly assigning them only as primary caregivers which makes it difficult to keep inclusion and gender equality in caregiving. I agree with Fraser by saying that if we acknowledge the diversity of gender power relations in caregiving, and encourage fair redistributive duties, and resource allocations, (Fraser,2007) it is possible to dismantle the gendered type of caregiving and achieve inclusion.

4.4 Challenges and Barriers in Caregiving

The participants shared stories regarding the challenges and barriers to mothers caring for children living with disabilities. However, it was hard to hear and recall the heart-breaking stories of these mothers, the data obtained from the mother's interview indicates a huge stigma leading to social exclusion which is often associated with having a child living with disabilities. This shows the difficulties of mothers in accessing support services as many judgmental attitudes are imposed on them. One of the respondents who has a 10-year-old child living with a disability said,

> "Oh it is not easy when talking about isolation, for example, when my child was sick, I had to go to the hospital alone without any family support even though I am from a big extended family. No one cares about me, and my son. She added, Sometimes I go into debt to pay for my son's hospital bills". (Interview,23th July 2024, Igunga).

From a total response of ten mothers caring for such children, nine of them shared similar stories. This shows how stigmatization pushes mothers into isolated responsibilities to navigate their roles.

Moreover, the in-depth interview of the mothers and focus group discussion with community members revealed negative beliefs and low community awareness about people with disabilities as the barriers preventing the mothers from providing care for their children living with disabilities. The findings show negative beliefs regarding disability, that still some community members believe disability is a curse from the gods due to the wrongdoing made by the mother, such as possession of witchcraft. This kind of belief sometimes makes husbands mostly neglect their wives leaving them with their children with less or no support from family, and community. In such a situation, mothers caring for a child with disability see themselves as inferior which negatively affects their psychological abilities and performance in their daily activities. This is reflected in some mother's behaviors as they do not want to participate in social grouping and communal activities. A mother of a child living with a disability stated:

> "My child was two years old when a neighbour, came and tried to convince me to throw my child in the river because she believed my child was not a normal child and would always bring bad luck to me and other community members. Even though I refused to throw him away, however, I have been thinking extent of truth that statement might be. Having a child is a celebrated thing in the community but not one with a disability. Sometimes, I felt very bad and cried all night, and even thought of taking me and My son's life to be free. However, I sometimes have another thought that the child may grow out of his current challenges"

She added questioning that,

> "How could one be so cruel?" (Interview,14th July 2024, Igunga)

Furthermore, according to the participant's responses collected, the lives of children living with disabilities and their mothers in the community are being made difficult by the negative mindsets about disability, hence discrimination against children and their mothers. This was mentioned as a serious challenge hindering mothers who provide care for their children, The mothers shared the heavy burden of family care which is overwhelming. Since they are indeed not only responsible for caring for their children living with a disability, but also for meeting the needs of their other children, such as providing school uniforms, food, clothing, shelter, and meeting life demands. For example, a mother with a deaf and dumb daughter among the respondents stated,

> "Mmmh. It's a difficult task that needs patience and struggle, just imagine a man running away from this heavy responsibility of taking care of a child living with disability and all duties are now relying on me as a woman" We were two people, and my husband runs away, how will it look when I am only now one person facing these challenges. I am the mother where will I run to and leave my child? I have to stay, if it is death then I will have to die with my child because she is my blood" (Interview,17th July 2024, Igunga)

Furthermore, as mothers often struggle to meet their children's demands, they extremely explain the ways financial barriers limit them to access the services for their children. They shared how their poverty situation limits to access health care services while mentioning that their children end up getting primary health care while they need specialized health services which are always high costs for them to access specialized hospitals. A mother said;

> "Sometimes life becomes difficult to afford the basic needs of the family and the child becomes helpless. I remember during the rainy season it was difficult to provide daily meals because always no market for my food vending business, it is very stressful" (Interview,21st July 2024, Igunga)

This shows how difficult it is for a mother to access health services for their children while failing to get even the basic needs such as food.

Participants' stories regarding the challenges mothers face were similar. However, in the FGD, the community members shared the challenges of early childcare education and communication with children living with disabilities, exposing that the program has failed to capture mothers caring for children living with disabilities. Their experience shows that these mothers encounter difficulties in communicating and looking after their children based on disability type and there is a lack of rehabilitation services. The participants explained that even if there is Early Child Care (ECC) intervention in the community, it is not designed specifically for mothers of children living with disabilities but rather for the community in general. So, it becomes difficult for mothers with children living with disabilities to access due to the negative perceptions and stigma. A man in the focus group discussion stated that,

> "My neighbour has a child with mental problems, sometimes she finds it difficult to understand her child. In her struggle, she was supported by the church to attend KCMC hospital with her child. The specialist links her to ECC education and services that could help along with the health services she gets, even though she is not accessing those particular services. I think ECC education is very important to these mothers on how to care for their children" (FGD,27th July 2024, Igunga)

Another community member agreed,

> "It is true, I was a community health worker, involved in Early Child Development (ECD) interventions but it was difficult to reach out to caregivers of children living with a disability because they don't come to health centers during education sessions and when I tried to visit them, I was not able to find them because they have a lot to do" (FGD,27th July 2024, Igunga)

Comparable to the participants, the lack of ECC interventions for families with children living with disabilities has the possibility to limit children's growth and increases the burden of care (Wang et al 2004, p.82)

Similar to the mother's experiences and community members' perspectives, practically in the Igunga district, I observed that lack of support and limited access to services contributes not only to the inability to access services but also to the marginalization of mothers and their children living with disabilities. It is commonly said that disability is not about inability, so mothers believe that their children may grow to contribute to society. However, I observed the infrastructure development does not support the free movement of children living with disabilities in schools, hospitals, or other public facilities. Even if they could have assistive devices like wheelchairs or white canes the accessibility remains difficult. I remember the instance when a mother and a child with multiple disabilities came to the office to pick up the wheelchair donated to them, when testing it, it got stuck under the sand around the office because the office building was not designed to facilitate wheelchair movement. I felt guilty and wondered if having a wheelchair would be helpful or not. However, the mother was happy saying that her house environment could support the wheelchair as there was no sand. It means that the wheelchair would reduce the burden of the mother carrying the child from one place to another only at home, and not in distant places such as schools, hospitals, and community activities because the roads do not support wheelchair movements.

These examples indicate how mothers need additional support beyond assistive devices, a fair redistribution of community resources (Fraser,1998) is significant for them and their children. Working in fieldwork and office activities I saw the multiple responsibilities of mothers in caregiving and the difference between mothers of children with disabilities and those without children with disabilities. Starting with hospitals I saw mothers who had a well-dressed child with no disabilities people enjoyed the child and often ask to carry, sometimes to play with the child. But a mother of a child living with disabilities when attending the hospital is not greeted in the same way and carries the child alone until she gets back home. All this shows the ways social -economic challenges force stigma on mothers and their children as also found by (Reimer-Kirkham et al,2020, p.721)

Visiting families of children with disabilities I observed the same, I saw mothers occupied at every angle doing household chores such as feeding the children, bathing them, and trying to communicate and play with them. Most of these families have poor housing conditions that do not even allow children to move from one place to another, so the mothers have to carry their children from place to place, especially those with physical disabilities and cerebral palsy.

From the above findings, there is no doubt that a child living with disabilities needs attention in terms of ensuring the necessary needs and services. All this demands time and financial resources. A situation of mothers alone in caregiving, while men run away from their responsibilities reveals a form of gender injustice (Home,2002). The stories of mothers show the burdens they carry, and the lack of support from families and the community prevents them from accessing information and participating in decision-making opportunities as well. Moreover, similar to Reimer-Kirkham et al (2024, p.719) and hidden challenges around disability, it is undeniable that the hidden mistreatment around disability (Uromi and Mazagwa 2014, p.158) affects mothers' well-being at individual, interpersonal, and systemic levels shouldering enormous burdens with little option to negative impact on psychological well-being.

4.5 Mothers' Needs and Existing Support Systems

Understanding the unique needs of mothers caring for children living with disabilities was a priority of this study. When sharing their daily struggles, participants consistently expressed demands that would ease their caregiving burdens and barriers. Their narratives also revealed gaps in available support structures that fail to recognize mothers' circumstances.

During interviews, mothers emphasized the urgent necessity of improving access to healthcare for their children's conditions. According to mothers, improved medical services including specialized health care and access to assistive devices for children living with disabilities can reduce their stress and burden on resources and time as they struggle to get money for transport, and accommodation when they attend far away hospitals.

A mother reflected on her experience by saying,

> "I remember when I was referred to KCMC hospital with my child, thinking about the cost while I had no transport to return home with my son, sometimes life becomes difficult to afford even basic needs" (Interview,16th July 2024, Igunga)

Access to referral health services was greatly proposed by all the participants, to reduce the burden of reaching out to health services without exhausting caregivers. A mother of a child with a mental disorder stated that,

> "With good intentions, the government built the hospital in our village, but I never had access to services regarding my child with disabilities every time I attended, they gave a referral form" (Interview,19th July 2024, Igunga)

Drawing from a decade of serving such families I witnessed mothers and their children struggling to access health services, especially after getting referral advice. The health service gaps indeed restrict equitable access and support in the district. Seeking specialist attention to children living with disabilities proved inactive, additional demanding children's long distances under lack of support to caregivers. Frequently, I realized the available health programs overlook how disability and distance intersect to marginalize remote mothers without flexible intervention and support to consider the situation and responsibilities of these mothers. Beyond distance and financial barriers to access specialized treatment, mothers require integrated services that address children's complications and specific needs.

Moreover, to reduce strain, economic empowerment through mothers' self-employment and grants emerged as a vital concern of all mothers. From the interviews, all mothers repeatedly said, they required economic empowerment and financial support but they could not always join what was provided in the community because of cultural barriers and the burden of care which did not allow them to access resources through group interventions.

As one mother of a child with physical disability explained,

> "Women's loans often target organized groups meeting monthly repayments. With full-time caretaking, I lack time for groups while small businesses add stress. We need flexible support without conditions" (Interview,3rd August 2024, Igunga)

On the same issue, a mother caring for a daughter living with a physical disability said,

> "Just imagine I joined the same economic group to get women's funds from the government with women who own the big clothes shops in Igunga market with their husbands. And who hires girls to work at home, and have normal children. I dropped from the group thinking that I was not fitting" (Interview,14th July 2024, Igunga)

From the participant's views, the study found that the current interventions overlook the mother's experience in caregiving. Moreover, limited mobility prevents mothers from participating in income-generating activities for their growth and survival. Furthermore, the mother's stories highlight the need for well-designed economic intervention with a gender-sensitive lens in caregiving to address the daily life experience of mothers caring for children living with disabilities.

Addressing psychosocial stresses on mothers' mental health also emerged as an important need from both interviews and FGD, the persistent demands of caregiving without relief cause excessive emotional pain according to participants. A mother of a child living with a disability stated that,

> "There are times when everything looks at you, the children, chores, and personal. You don't know where to start...Sometimes life becomes too difficult." (Interview,16th July 2024, Igunga)

Another story from a mother of a child with mental and cerebral palsy cemented the need for psychological and counseling support for mothers caring for children with disabilities, she said,

> "Some nights, I can't sleep thinking about my daughter after everyone else does. I feel alone in this, fearful of her future though determined to keep caring as a mother should. Yet the worries never end, my family and community fail to see our pain" (Interview,19th July 2024, Igunga)

The above perspectives highlight the need for psychosocial support, counseling, and recognition of emotional burdens to avoid the consequences of persistent stress and isolation that can impact mother's well-being due to stigma and lack of support. In addition to that, their stories revealed the need for extra outreach activities regarding mental health programs and support to families living with individuals living with disabilities.

Furthermore, the study finds a need for local programs, particularly for mothers and children with disabilities. The participants in FGD explained the extreme and unequal concentration of programs on group-based interventions rather than individualized outreach to most people in need. According to community members, the group interventions are the reasons mothers remain largely invisible in program design and implementation. During the group discussion, one of the community members said,

> "Take an example of TASAF program, they select people through community gatherings, which is unfair to mothers who stay at home daily with their children, and most of the time they have no information about what is going on in the community" (FGD,27th July 2024, Igunga)

Moreover, the need for fair distribution of services and resources to the marginalized family who lives and provides care for children with disabilities is highlighted by both participants. A social welfare officer said,

> "In our social welfare section, we are working under a very minimal budget that can't meet the demand of the marginalized. I know, for the case of mothers caring for children living with disabilities, they need a comprehensive fair distribution of resources and easy-to-access services, and that is what we are asking for our leaders" (Interview,29th July 2024, Igunga)

Community education and awareness emphasized by the participant to reduce the stigma around disabilities. Both groups shared similar views regarding needs and support. The focus group discussion highlighted the need for increased local community awareness against stigma to mothers and their children to access social and economic support. From their perspective, I found that the grassroots individuals live under limited education and still are the ones who are suffering. The participant's discussion insisted on uprooting the persisting cultural beliefs and traditions attached to caregiving under a male-dominated system that requires local community awareness about disability and care, against the stigma and oppression.

During an in-depth interview, a neglected mother because of her child, in a sad voice said,

> "I hope that if my family-in-law and the neighboring community understand about disability, and what I am going through with my child, one day we will feel as part of this community". (Interview,3rd August 2024, Igunga)

As a social welfare officer close to marginalized families, I observed gaps hindering mothers' abilities to access important needs for their children. Similar to the participant and social welfare officer, in my fieldwork, I have seen these overburdened mothers frequently request food, clothing, and medical cost assistance. These are critical needs that welfare offices couldn't meet under funding restrictions. However, in performing my duties referral and linkages are an alternative for mothers to get support. I linked these families to faith-based organizations such as churches and mosques for support but in most cases, I lack assurance of support and how long it could take for them to get support, the fact that they often need urgent support.

Additionally, the social welfare structures work in collaboration with the government and other stakeholders, seeking their support as a duty bearer, I was often disappointed when I talked to NGOs for support and responded that the clients are not among the targets of the funding project. In the district, the government allocates 10% to support, youth, women, and people living with disabilities. However, to access the fund, a mother should have a registered economic group. When I was linking the mothers to access funds, I noticed most of them do not meet the requirements and often need direct individual support depending on their particular needs which is difficult to access.

In addition to that, the experience shared by the mothers and the community members about the needs and support system resonates greatly with my reflection on the three cases of mothers who needed multiple support systems for giving care of their children, but I ended up providing them with psychological counselling support. With this study, I realize the great need for financial support to ensure the mother's and children's well-being. Bringing here the argument of Mc Nally and Mannan (2013.p.2), mothers indeed feel compelled to be alone due to life experiences and personal circumstances beyond their control, therefore structural support and individual capacity to meet their obligation of care are mostly important. It is also supported by WHO's reaction to the financial commitment to individuals living with disabilities (Olusanya et al,2023, p.8)

In summary, participants' narratives and my experiences emphasized the need to have a complete individual supportive system by incorporating health services, economic empowerment, psychosocial support, and responsive community programs focusing on meeting the needs of mothers caring for children living with disabilities.

4.6 Understanding the Life of Mothers in Caregiving

Understanding the daily life of mothers caring for children living with disabilities was my focus in this study, thus the participants' stories were more relevant and motivating to know the mothers' lives. During an in-depth interview, the mothers explained the changes and suffering in their lives that started after giving birth to children living with disabilities. Through their stories, the study found that the nature of caregiving shapes the daily lives of mothers, and because of stigma and wrong beliefs, they often live with their children alone. Moreover, to meet caregiving demands mothers engage in other activities such as farming, and small business, while mothers without income alternatives live in extremely poor and are often street beggars. According to mothers, different from men who never experience isolation or changes in care responsibilities, they live in an exclusion environment in the family, close friends, and community because of having children living with disabilities.

The below statements from the mothers of children living with disabilities elaborate on the nature of their daily lives;

The first mother said,

> "The hospital trips and visits started after the birth of my daughter, and until now I never stopped going to the hospital". (Interview,15th July 2024, Igunga)

Another woman with a mental and physical disability child added that,

> "Most of the time I am with my child to make sure he is clean; he eats and I don't leave him to anyone as no one accepts to stay with him" (Interview,23rd July 2024, Igunga)

Besides, the woman caring for a child living with disabilities cemented by sharing her life after giving birth to her child at the hospital.

> "The most complicated situation in my life, I remember is when I gave birth to a child with a disability, even my mother-in-law did not visit me in the hospital. She added that I learned that being a mother with a disabled child and poor is more difficult while blaming myself for why I got married. This situation applies to all mothers like me, it happens because everyone despises me with stigma and often called a curse, but If I could have money people's words wouldn't hurt because I can afford caregiving" (Interview,21st July 2024, Igunga)

Moreover, the above statements signify the everyday stigma attached to mothers' lives. Also, their stories reveal that a woman's life in society can change at times and become painful if she gives birth to a disabled child, which is totally unfair.

Furthermore, the study found that the daily lives of mothers depend on the child's situation, disability type, and demands. The mothers live an unpredictable life, they explained about unreliable day schedules every morning they wake up. Listening to their daily life experiences, some mothers looked tired and disappointed even though they still had the patience to raise their children. The fact that their situation is different from others, their stories reveal the dilemma, anxiety, regret, fear, and trauma that appear to be part of their life. According to them, their daily routines are largely tired and occupied. Because of stigma, no one helps them to look after their children. Through their stories I find that mothers' routines allow no happiness leisure or rest, their lives appear extremely tough without relief or break. Likewise, the ongoing misconceptions about disability led them to lack confidence in engaging with the community as they live an isolated life due to stigma.

A mother of a child living with a disability said,

> "One day, in the morning I found my child's room smelling, as a mother I felt shedding tears. Then the schedule of the day was disrupted, imagine that I started bathing him, washing clothes, and even cleaning the room, also required to work in order to get money" (Interview,15th July 2024, Igunga)

Also, a mother who provides care to four children including one living with disabilities stated,

"Sometimes I opt to be patient and flexible, because of home activities, I cannot attend to my business at the right time, sometimes I go just for a short time, apart from cooking for them, as they should find food after school, I have to take my child to school in the morning and to bring her at home at noon" (Interview,19th July 2024, Igunga)

Similar to mothers' narratives, drawing back on my office work, I have seen mothers and their children living with disabilities under neglect and stigma in daily life. Frequently they report neglect and stigma cases to the social welfare office asking for mediation and support. Responding to these cases, I realized that the abandonment is not only by the husband, also they lack family and community support due to humiliation and dominant wrong beliefs. Correspondingly, both mothers in in-depth interviews and community members described mothers' lives in connection to poverty, isolation, and stigma around them. The mothers shared that poverty has been part of their lives and that it is normal for them to live without being sure of the daily meals for their children. Adding to that, community members explained that mothers caring for children living with disabilities live in hardships, often found around the street asking for help. From the participants' narratives, I found that some women have small businesses for income, while others do not have a job or any source of income. However, mothers with extra sources of income still don't have time to engage fully.

In addition to participant perspectives, as part of the community, I have seen mothers carrying their children on their backs along the road asking for help, also attending church, mostly I have been participating in contributing to marginalized groups such as women and their living with disabilities. Moreover, as a social welfare officer responsible for serving them, I frequently linked mothers to get legal permission to ask for fundraising from people to meet their children's needs. Often, these are mothers whose children need medical services at referral hospitals, and they are unable to afford the cost of care, normally they receive a supportive document from the district office. Even though they received permission to ask for support from people, often I saw them going around the street, entering different offices the whole day without receiving any assistance or support. In all these situations of my experience, I deeply realized that the real day-to-day picture of a poor woman burdened with the sole responsibility of caregiving is evolving at the risk of stigma, exclusion, and poverty. Moreover, I reason that the unclear supportive structure regarding mothers and their children continues to reproduce the hidden gender oppression (Home,2002), placing mothers in the cycle of poverty and reliant life.

In the same way, the study shows that mothers live with nervousness and uncertainty concerning exclusion. Mothers' stories and my own experience show the dilemma of living within the predominant attitude regarding disabilities as they know that they have done nothing wrong to be cursed. Therefore, their everyday struggle is to get out from exclusion. Usually, they attend to local healers believing that their lives and children's condition could be better.

A mother of a child living with multiple disabilities explains this uncertain life by saying,

> "I took my son to a local traditional healer in Ukerewe-Mwanza after being told that he would treat my son and remove the curse and misfortune around me and my family. I stayed in Ukerewe with my son for three months, and every day my son was given drugs to drink and cleanse. But I realized that the person was a witch and not a local healer because my child had not recovered" (Interview, 23th July 2024, Igunga)

Relating to the above statements, I also worked at the hospital as a social welfare, I observed mothers asking for their children to be discharged from hospitals while in serious situations of sickness believing and aiming to go to traditional healers. I find that mothers live uncertain lives because of stigma forces whereby mothers fight to get through even in a wrong way, and unknowingly. Moreover, the above voices highlight mothers' lives around negative beliefs that force mothers and children to enter risk environments that can also affect their lives.

In addition, the uncertain and worried life of mothers caring for children living with disabilities, and frustration dominate their lives (Ambikile and Outwater,2012, p.9). Bringing in my experience, I reflect on the case of a man who was killed while defending his wife living with albinism in the Igunga district. I remember the incidents threatened the whole community and families who live with such kind of people with albinism. Also, I reflect on the current case of the brutal killings of Asimwe, an albino child in the next community which happened one month before I conducted my study. I experienced tension, uncertainty, and fear in every member of the community after these inhuman incidents.

However, it is difficult to imagine how hard it is for the life of a mother caring for children with albinism alone in a community where albino killings are trending. All of these reveal the insecure life of mothers caring for children with disabilities mostly with children living with albinism. Similarly, from the three cases of my experience, If I draw one case a mother who brought her beautiful albino child to me proposed to leave her child with me in the office just because of insecurity and hardship. I remember the mother was crying, I found myself very hurt. I see that some mothers would like to live with their children but they are not sure about their survival, every time, day and night they are at risk of being attacked because of their children, a threatened life, and injustice practices on going in sub-Saharan countries (Likumbo, et al,2021, p.5). Through the findings, I see the unfair life around women who provide care to children living with disabilities as undesirable to any human being. However, I accept that behind caregiving is love and feelings of concern in attending to the individual in need (Cancian and Oliker,2000, p.2).

In conclusion, the fact that the daily life of mothers caring for children living with disabilities is shaped by society through negative beliefs, stigma, exclusion, and single-handed caregiving, women are suffering every time in their lives. Based on the participants' narratives and my own experience I comprehend that because of the already constructed life, mothers' daily lives are uncertain and continue to evolve in the poverty cycle because of unequal structures.

Chapter 5: Conclusion, reflection, and Way Forward

This chapter gives a brief about the whole research. Involves a reflection, a brief research overview, and a response to research questions based on the chapters. It also proposes ways better for an equitable outcome.

The fact that this research is based on the lives of mothers who raise children with disabilities also reflects on my life and experience of welfare systems that work to ensure, protection, support, and services to special groups, and mothers caring for children living with disabilities in particular. Doing this research is not only for fulfilling my studies but also for achieving my dream of helping women who raise children living with disabilities, with their voices to be heard for inclusion. Undertaking social welfare work and being close to these women for decades, considering that I am at ISS studying human rights, gender, and conflict studies I found myself motivated to bring women's voices through this research. The fact that I am also a woman who would not like to see other women suffering from gender attitudes and discrimination because of natural circumstances.

In the previous chapters, I tried to show how a woman has been assigned to be a primary caregiver and how mothers are burdened with caring for children living with disability alone in a situation of desertion by husbands, stigma, isolation, and lack of support from family, the community and government structures. I have also tried to bring out the fact of feminist thinking on care, reflecting the circumstances of children living with disabilities and mothers in caretaking in the study context. It is possible to agree that care is essential for survival and enhancing social relationships (Harcourt, 2023.p.3). Therefore, I realize that encouraging visibility and revaluing care can significantly reduce the burden on mothers as primary caregivers. From mothers themselves, we have also seen the way the patriarchal system reproduces gender thinking which places women as the main caregivers from their childhood to adulthood. To understand further how mothers navigate livelihood for themselves and their children the study has responded following my research questions;

Starting with the challenges, the research has revealed the great burdens placed upon mothers through social stigma, poverty, and lack of support to ensure the constant demands of caregiving. In the whole research, the existing stigma forces mothers to be isolated within families while separating them from community relationships and resources. We have also seen how social exclusion subjects' mothers caring for children living with disabilities to loneliness and dilemma in navigating livelihood for themselves and their children. Moreover, I have found the extreme poverty for the families of children living with disabilities and the existing stress on mothers who provide care with no option of support systems. Through participants' stories and my own reflections, I discovered that too much time spent caring for children limits mothers to work for alternative income, as they are failing to attend even their small businesses.

The study further informs the specific types of support that could ease challenges and barriers to meet the needs of mothers in caregiving. The integrated health services have revealed the highest importance to address children's diverse conditions through improving referral services systems in order to minimize mothers' cost burden. The fact that specialized health services are unavoidable for a child living with disabilities, however, is still limited. Financial support without conditions of group loans was emphasized to free women from accessing government loans and grants. Despite the prevailing cultural norm about disability and care. through participants' views, the study highlights the need for local community awareness regarding disability that could minimize negative beliefs and stigma, to promote assistance to mothers caring for children with disabilities.

In the situation of mothers caring for children living with disabilities around negative beliefs stigma, and exclusion; some of them are judged for wrongdoing, sin, and curse. In normal thinking and limited interaction, it is difficult to imagine how hard life is to have a child living with disabilities and also to understand how the daily life of a poor woman in the care of a child living with disabilities looks. This creates a reason to recognize the surrounding environment to caregiving aiming at improving the mothers' future lives.

However, it gives emotive; In the previous chapter, the study highlighted the true life of mothers who live non-stop caregiving to meet the demands of their children. Moreover, in particular, the study, informs the uncertainty, isolation, and stress being part of mothers' lives. As marginalized, in extreme poverty environments as well, mothers became street beggars for their children's survival, which is very painful. While the mothers of albino children live in fear of attack and killings of their innocent children feeling that they are in danger. On the other hand, it shows the remarkable resilience of mothers in poverty, risky environments, and psychological circumstances as their daily struggle aims to get out from exclusion.

Reflecting on my academic journey and now as a researcher, this research has expanded my knowledge concerning equitable life. Following the viewpoint of addressing the equitable outcome, from the nature of the study findings I found the significance of Fraser's concepts on challenging gender injustices suggesting looking forward to both distributions of resources and recognition of mothers' experience in caregiving around cultural forces (Fraser,2008, p.2-3; 2007, p24- 25). The perspective that emerged regarding fair life was an intervention that would consider the mother's experiences in caring for children living with disabilities. Because their life is unshared, specific consideration has significance to uplift the mother's life. Increasing the value of care, resource distribution, and recognizing women's roles is a possible way to gender justice.

Moreover, concerning the findings about a just outcome, establishing a local organization only for mothers caring for children living with disabilities could help strengthen community relationships, skills development, and comprehensive advocacy on policy issues. As we have seen the suffering of these mothers; unequal access to resources, poverty, negative beliefs, and limited welfare systems. Recognizing mothers through the organization is a way to promote well-being and self-independence, and community support and empowerment would play a part in an equitable life. Moreover, it is very possible through an organization to have easy communication and the right information for accessibility of mothers and their children living with disabilities for better support.

Drawing from participants' perspectives, connecting to Fraser (2007, p.33), cultural transformation is important to revalue caregiving through women's organizations parallel with redistributive policies to remedy misrecognition and enhance mothers' well-being. Moreover, the study has informed the inclusive gap in the programs, policies, and guidelines. It also raises concerns about integrating the policies and programs to support women's development, well-being, and gender equality in the context of caregiving to children living with disabilities in Tanzania

To conclude, when I reflect on this study about the lives of mothers caring for children living with disabilities, I comprehend Fraser's perspective that "no redistribution without recognition" (2007, p.33). Accordingly, I see nothing is impossible only if it is well intended. Therefore, achieving a just society, is significant for mothers' welfare, observing the equal distribution of resources and recognizing mothers' cultural roles are important to improve them as primary caregivers. Thus, to make this possible is more relevant to have policies and programs that effectively address the social protection issues of children and women and in caregiving.

Lastly, I see and recommend the need to rethink and apprehend that when planning, the distribution of resources should first focus on mothers.

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Appendices

Appendix 1. Questionnaire Guide: Mothers Caring for Children Living with Disabilities (In-depth interview)

Self-Introduction

I am conducting this study as a part of my academic studies at the Erasmus University of Rotterdam in The Netherlands. On the issue of Unrecognized Labour for Mothers caring for children living with disabilities. The objective of this research is to understand the daily life experiences, challenges, and specific needs of these mothers. Your participation is voluntary and your information will be kept anonymous and confidential.

Before our discussion, I would like to ask for your consent to take notes and record your voice.

1. Can you kindly tell me about you?
   Probes... About your name, age, your family and other siblings, marriage status, and background, education)
2. what about your child living with a disability?
   Probes (history, daily activities, caring for the child)
3. What do you understand about caregiving?
   Probes… caring role to mother, father, and community.
4. To what extent does caring for your child, affect your well-being and relationship?
   Probes. On health, social, economic, family life, and other relationships.
5. What are the possible challenges you face in providing care for your child?
   Probes…. On the support, and specific needs.
6. How does your community view your child and your role as a mother?
   Probes…on beliefs, norms, and caring role.
7. Can you explain how you participate in making decisions regarding your life and caring for your child?
   Probes….in family, community, participation.
   Probes….resources allocations, access to services
8. In what ways do you feel your role of caring for your child is recognized or not recognized?
   Probes…. On family, community perceptions, and government response.
9. What changes or interventions would you like to see in policy and programs to improve the lives of mothers like you?
   Probes.... on, access to service, resource distribution, health, education.
10. What are the strengths and hopes in caring for your child despite the challenges you face?
    Probes... Information, cultural norms, social, and economic engagement.
11. What do you think about the contribution of this study to your life experiences?
    Probes...education, resource allocation, policies, etc
12. Can you kindly speak about your future aspirations?

Appendix 2. Questionnaire Guide: Community Focus Group Discussion (FGD)

Self-Introduction.

This research is conducted as a part of academic studies at Erasmus University of Rotterdam. My issue is on the Unrecognized Labour for Mothers caring for children living with disabilities. The objective of this research is to understand the daily life experiences, challenges, and their specific needs. Your participation is voluntary and your information will be kept anonymous and confidential.

Asking for consent of participation, and recording.

1. What does caregiving mean to you, and in your community?

Probes... (primary caregivers in the family)

2. What are the particular activities behind caregiving?

Probes... (in family and community)

3. How do mothers become the main caregivers of children living with disabilities?

Probes...(contributing factors...)

4. What are your experiences of the challenges faced by mothers caring for children living with disabilities?

Probes....(supporting systems and particular needs)

5. What are the common perceptions in the community about disability and mothers caring for children living with disabilities?

Probes... (beliefs and norms)

6. How do you think caring for children with disability can be possibly a shared responsibility?

Probes...what can be done in terms of culture, norms, policies, and intervention?

7. What do you think are opportunities to promote more inclusive and equitable outcomes for these mothers and their children?

Probes...health, education, economic, social, and cultural recognition.

Appendix.3 Questionnaire Guide: Social Welfare Officer (In-depth interview)

Self-Introduction

This research is conducted by, Alice Mlaki, a student at Erasmus University of Rotterdam in The Netherlands. On the issue of Unrecognized Labour for Mothers caring for children living with disabilities. The objective of this research is to understand the daily life experiences, challenges, and specific needs of these mothers. Your participation is voluntary and your information will be kept anonymous and confidential.

Before our discussion, I would like to ask for your consent to record your voice.

1. Can you kindly explain how caregiving is understood in your position as a social welfare?

Probes…. (caring roles, parents, husband, wife, community)

2. What is the nature of cases you attend regarding caring for children with disabilities?

Probes....neglect, single parenting, maintenance.

3. How do cultural norms and power dynamics influence the perception of caregiving for children living with disabilities?

Probes...assigned-caring role to women and husbands,

4. How do the available policies and programs engage the issue of mothers caring for children living with disabilities?

Probes... education, economic distribution, gender empowerment programs, etc.

5. What do you think, are the main challenges mothers caring for children with disabilities face?

Probes... supports systems, particular needs.

6. How do you address these challenges as a social welfare officer?

Probes... access to services systems eg, health, education, psychosocial counseling, community networks, linkages, etc.

Probes.... reporting, and professional advice to working structures.

7. In your professional opinion, what are the most critical changes needed in policies, programs, resources, or attitudes in promoting an equitable society?

Probes.... contribution of the study findings, and policies and interventions.

8. Do you have any information or perspectives for more understanding and improving support for these mothers? Please feel free to share.

Appendix 4. ISS Research Ethics Review Form

ISS Research Ethics Review Form for
RP research carried out by MA students[1]

Aim:

This Form aims to help you identify research ethics issues which may come up in the design and delivery of your Research Paper (RP). It builds on the session on Research Ethics session in course 3105 and subsequent discussions with your peers and RP supervisor/reader. We hope the form encourages you to reflect on the ethics issues which may arise.

The process:

The Ethics Review process consists of answering questions in the following two checklists: B1-Low-sensitivity and B2-High-sensitivity. Depending on the answer to these questions you might need to fill section **C-Statement of Research Ethics** too.

The background document "ISS Research Ethics Guidelines for MA Students" provides advice and detailed information on how to complete this form.

Step 1 - Fill checklists B1 and B2

Step 2 - After answering checklists B1 and B2, the process proceeds as follows:

- **If you answer 'yes' to one or more low-sensitivity questions (checklist B1):** please discuss the issues raised with your supervisor and include an overview of the risks, and actions you can take to mitigate them, in the final design of your RP. You can refer to the ISS Research Ethics Guidelines for MA Students for help with this.

- **If you answer 'yes' to one or more high-sensitivity questions (checklist B2)**, please complete section 'C' of the form below describing the risks you have identified and how you plan to mitigate against them. Discuss the material with your supervisor, in most cases the supervisor will provide approval for you to go ahead with your research and attach this form to the RP design when you upload it in canvas. If, after consultation with your supervisor, it is felt that additional reflection is needed, please submit this form (sections B1, B2, and C) to the Research Ethics Committee (REC) for review as follows:

  When submitting your form to the REC, please send the following to researchethics@iss.nl:

  1) the completed checklists B1 and B2 (or equivalent if dealing with an external ethics requirement)
  2) the completed form C 'Statement of Research Ethics'
  3) a copy of the RP design
  4) any accompanying documentation, for example, consent forms, Data Management Plans (DMP), ethics clearances from other institutions.

  Your application will be reviewed by a reviewer who is not part of your supervisory team. The REC aims to respond to ethics approval requests within a period of 15 working days.

Step 3 - Integrating the Ethics Review process into the RP:

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[1] This checklist and statement is adapted from the Institute of Development Studies (IDS) Research Ethics Committee and informed by the checklists of two Ethics Review Boards at EUR (ESHCC and ERIM) and the EU H2020 Guidance – How to complete your ethics selfassessment.

- This Ethics Review Form (checklists B1 and B2) needs to be added as an annex in your RP Design document to be uploaded in the Canvas page for course 3105 and to be presented in May.

- If, as a result of completing sections B1 and B2 of this Review Form you also need to complete section C , add section C ‘Statement of Research Ethics’ and Section D ‘Approval from Research Ethics Committee’ (if available) as an annex to your final RP design to be to be uploaded in the Canvas page for course 3105 in
July.

Project details, Checklists, and Approval Status

A) Project/Proposal details

1. Project/Proposal Title	Unrecognized labor: Mothers caring for children living with disabilities in igunga district, Tanzania.
2. Name of MA student (applicant)	Alice Boneventure Mlaki
3. Email address of MA student	643151am@student.eur.nl
4. Name of Supervisor	Prof. Dr. Wendy Harcourt.
5. Email address of Supervisor	harcourt@iss.nl
6. Country/countries where research will take place	Tanzania.

7. Short description of the proposed research and the context in which it is carried out:

In Tanzania, the studies find that mothers are the primary caregivers in the family. Despite caring being a burden to all mothers, mothers caring for children living with disabilities in Igunga district experience a double burden compared to other women. As a social welfare officer in this district, I often experience social isolation, limited support, and an overwhelming burden when they struggle to meet the caring demands of their children, as they are also required to participate in farming activities to get food to satisfy their families. This situation upsets me because no mother deserves to bear such a great load by herself.

Despite the initiatives of women's empowerment to reduce the burden of caring.

Their voices are silent, no one listens to their voices, sacrifices, and struggles for these innocent children.

The demands of these mothers are frequently ignored.

Yet the intervention and the available policy fail to address the issue of caring burden.

The literature available lacks an understanding of the daily experiences, challenges, and specific needs, particularly for mothers caring for children living with disabilities.

Therefore,

In this research, my goal is to reach a stage of respecting the resilience of these mothers and facilitate support for their important caregiving work, which is so often taken for granted.

Main objective to explore the daily life experience of mothers caring for children living with disabilities focusing on social justice and gender justice concerns in the context of caregiving in Igunga district, for equitable society.

The research context

Tanzania's rural area, particularly Igunga district..

Qualitative research methodology through focus group discussion with mothers who experience care and mothers caring for children with disabilities, as well as social welfare officers.

B) Research checklist

The following checklist acts as a guide to help you think through what areas of research ethics you may need to address. For explanations and guidance please refer to the background document 'ISS Research Ethics Guidelines for MA students'. Please complete both sections (B1 and B2)

Please tick the appropriate box	**YES**	**NO**
B1: LOW-SENSITIVITY		
1. Does the research involve the collection and or processing of (primary or secondary) personal data (including personal data in the public domain)?	☑	☐
2. Does the research involve participants from whom voluntary informed consent needs to be sought?	☑	☐
3. Will financial or material incentives (other than reasonable expenses and compensation for time) be offered to participants?	☑	☐
	☑	

4. Will the research require the co-operation of a gatekeeper for access to the groups, communities or individuals to be recruited (e.g., administrator for a private Facebook group, manager of an institutions, government official)?		☐
5. Does the research include benefit-sharing measures for research which takes place with people who could be considered vulnerable? – please revise the background document (Guidelines) for more information.	☑	☐

If you have ticked 'yes' to any of the above boxes (1-5), please discuss with your supervisor and include more information in your RP design describing the issue raised and how you propose to deal with it during your research.

B2: HIGH SENSITIVITY	**YES**	**NO**
6. Does the research involve the collection or processing of ***sensitive*** (primary or secondary) personal data? (e.g. regarding racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union membership, biometric data, data related to health or a person's sex life or sexual orientation)	☐	☑
7. Does the research involve participants for whom voluntary and informed consent may require special attention or who can be considered 'vulnerable'? (e.g., children (under 18), people with learning disabilities, undocumented migrants, patients, prisoners)?	☐	☑
8. Will it be necessary for participants to take part in the research without their knowledge and consent (covert observation of people in non-public places)?	☐	☑
9. Will the research be conducted in healthcare institutions, in healthcare settings, or will it involve the recruitment or study of patients or healthcare personnel?	☐	☑
10. Could the research induce psychological stress or anxiety or cause harm or negative consequences for research participants, researchers, or persons and institutions connected to them?	☐	☑
11. Could the situation in one or several of the countries where research is carried out put the researcher, individuals taking part in the research, or individuals connected to the researcher, at risk? Presence of an infectious disease such as COVID-19 is considered a risk – please provide information as outlined in the background document (Guidelines).	☐	☑
12. Does the research require ethical approval or research permission from a local institution or body?	☐	☑

If you have ticked 'Yes' to one of the above (5-11), please complete section 'C' below describing how you propose to mitigate the risks you have identified. After discussion with your supervisor, please submit the form to the Research Ethics Committee. In addition, if you have ticked 'Yes' to a question on any kind of personal data, please also complete the privacy questionnaire.

YOU ONLY NEED TO COMPLETE THIS SECTION IF YOU HAVE ANSWERED YES TO ONE OF THE QUESTIONS IN SECTION B2 ABOVE (Questions 5-11)

C) Statement of Research Ethics

Using the background document 'ISS Research Ethics Guidelines for MA students', please address how you are going to deal with the ethics concern identified, including prevention measure to avoid them from manifesting, mitigation strategies to reduce their impact, and preparedness and contingency planning if the risks manifest.

Please number each point to correspond with the relevant checklist question above. Expand this section as needed and add any additional documentation which might not be included in your RP design, such as consent forms.

[TO BE COMPLETED BY MA STUDENT AND DISCUSSED WITH THE SUPERVISOR. IF THE SUPERVISOR FINDS IT NECESSARY TO SEEK FURTHER REVIEW, THE STUDENT MUST SUBMIT THE FORM TO THE RESEARCH ETHICS COMMITTEE]

D) Approval from Research Ethics Committee

*To be completed by the Research Ethics Committee only if

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Approved by Research Ethics Committee:

Date: 13/06/2024

Additional comments for consideration from Research Ethics Committee:

If the REC needs more information before approving, the REC secretary will be in touch with the MA student. If after requesting more information the REC still has concerns, the REC secretary will ask the supervisor to discuss these with the student. In the unlikely event that there is still no resolution, the REC will refer the application to the Institute Board.