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## Impaired child, disabled parent?

Parents' perceptions of having a child with disability in Dar es Salaam, Tanzania

Author: Elise Johansson  
Supervisor: Kristina Jönsson

## ABSTRACT

Having a child with disability (CWD) gives rise to implications for the parents. Social and psychological challenges are known factors, together with financial constraints and employment issues, which increase the risk of poverty. Therefore, the aim of this study was to explore parents' perception of and how their lives have been impacted by having a CWD. The methods consisted of semi-structured interviews and focus group discussions with parents of CWD specifically in Dar es Salaam, Tanzania. The ecological theory structured the analysis and used the concepts of stigma, marginalization and normalization to understand parents' perceptions. Challenges described by parents were lack of governmental support, insufficient public services, the burden of care and financial issues. Opinions and reactions from society were stigmatizing and resulted in strained relationships with neighbors, friends and relatives. The feelings involved were worry and sorrows, but also hope, love and happiness. The found coping strategies were mainly to strive for public services and sufficient income, in combination with acceptance, retaining hope and turning to God. The study concluded that even if the parents were not impaired themselves, their experiences were many times similar to that of a person with disabilities.

**Keywords:** disability, parents, children, marginalization, stigma, ecological theory, Tanzania

**Word count:** 14 993

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## LIST OF ACRONYMS

CWD	Child With Disability
FGD	Focus Group Discussion
ICF	The International Classification of Functioning, Disability and Health
MoLYDS	Ministry of Labor, Youth Development and Sports
NBS	National Bureau of Statistics (Tanzania)
PDA	Persons with Disabilities Act, 2010
PWD	Persons With Disability
WB	The World Bank
WHO	World Health Organization

## CLARIFICATIONS OF WORD USE

Child	the word is used in the sense of being someone's child, not relating to having a specific age.
Disability	to describe the child's situation, singular of the word disability is consistently used, regardless of the child's diagnosis, that is, whether if the child has one disability or several disabilities the same word is used.
Family member	for the simplicity in this study, family members are used in the sense of those who share housing, that is, family members equals household members.
Impairment	WHO's (2001:19) definition is used when referring to the term; "[i]mpairments are problems in body function or structure such as a significant deviation or loss". Impairment can be congenital, such as mental impairments or spinal bifida; it can also be acquired during life, due to injury or disease. Impairment is not to be equated with disability, further discussed in section two.
Parent	when used in this study, the word parents also includes those who are the primary caregivers of the CWD. In the analysis we find, for example a brother, grandmother and uncle who are included in the word parent.
Relatives/ extended family	include all relatives not living in the same household as the person they relate to. The terms relatives and extended family are used interchangeably.

# TABLE OF CONTENT

Abstract .....	I
Acknowledgement.....	II
List of acronyms.....	III
Clarifications of word use .....	III
<b>1. Introduction .....</b>	<b>1</b>
1.1 Field of research .....	1
1.2 Aim and research question .....	2
<b>2. Disability contextualized .....</b>	<b>3</b>
2.1 Defining disability .....	3
2.2 Magnitude and legislation .....	4
<b>3. Previous research.....</b>	<b>5</b>
<b>4. Theory.....</b>	<b>8</b>
4.1 The ecological theory .....	8
4.2 Theoretical concepts .....	9
4.2.1 Coping.....	10
4.2.2 Stigma .....	10
4.2.3 Marginalization.....	11
4.2.4 Normalization .....	11
<b>5. Methodology.....</b>	<b>12</b>
5.1 Research approach.....	12
5.2 Research participants: identification and data generation .....	12
5.2.1 Identification strategy .....	13
5.2.2 Data obtaining and the participants .....	14
5.3 Interpretation and transcription .....	16
5.4 Method of analysis.....	16
5.5 Trustworthiness of the study.....	17
<b>6. Analysis.....</b>	<b>18</b>
6.1 Structural level.....	18
6.2 Community level .....	20
6.2.1 Health care .....	20
6.2.2 Education .....	21
6.2.3 Work situation for the parents .....	23

6.2.4 Physical and social environment.....	23
6.2.5 Living situation in relation to neighbors.....	24
6.2.6 Extended family and friends .....	26
6.2.7 Support and reactions from other sources.....	27
6.3 Relational level.....	28
6.3.1 The daily care for the child .....	29
6.3.2 Future concerns.....	29
6.3.3 Family situation .....	30
6.3.4 Financial situation of the household .....	31
6.4 Individual level.....	33
<b>7. Conclusion.....</b>	<b>35</b>
Appendices .....	44
Appendix 1 – Interview guide for FGD.....	44
Appendix 2 – Interview guide for individual interviews.....	45

# 1. INTRODUCTION

## 1.1 FIELD OF RESEARCH

Giving birth to a child with disability (CWD) or experiencing a child acquiring disability is rarely an expected event in a family. Nevertheless, it generates implications for the child as well as for the surrounding family, particularly for parents. A review by Waldman et al. (2010:619) states that raising a CWD is connected with hardships for the family, including economic, social, and psychological issues as well as intra-family conflicts, issues of time-utilization and employment. To limit unnecessary suffering and enable provision of appropriate social support and professional interventions, it is crucial for the surrounding community including the family and friends, service providers, and policy makers to have a deep understanding of the challenges that affect parents of CWD (Algood et al. 2013:132; UN, 2013a:5-6). This study aims to explore how parents of CWD, in the specific context of The United Republic of Tanzania (Tanzania), perceive their situation, in terms of challenges they experience, related coping strategies and their interaction with society where they live.

Several challenges are known for persons with disability (PWD) in Tanzania. CWD face difficulties accessing and remaining in school due to physical barriers and teachers' lack of understanding, knowledge and training in how to teach disabled children (Mkumbo, 2008). Aldersey et al. (2011) found that discrimination against people with disabilities continues when searching for employment and by employers when finding a job. There is also a lack of rehabilitation, healthcare and other social services for PWD in the country (Mbwilo et al., 2010 and Njelesani et al., 2011). Both Mbwilo et al. (2010) and McNally and Mannan (2013) found parents of CWD in Tanzania to be in great need of support such as health care, financial support and education for their child. Tanzania's Persons with Disabilities Act (PDA), 2010 points out a need to reduce stigma both among people with disabilities and for their immediate family, indicating stigma is most likely a problem for these groups. Although needs for CWD are somewhat explored, only limited research have been conducted on the situation for parents of CWD in the Tanzanian context.

Disability often remains invisible in society, even if a relationship between development and disability is well known. Higher disability prevalence is indicated for lower income countries than higher income countries, and an estimated 80 percent of people with disabilities live in developing countries (UN, 2013b:2). This indicates a relation between disability and poverty

(WHO and the World Bank (WB), 2011b:8). This can be seen through at least two different perspectives. First, individuals and families experiencing higher rates of poverty are more vulnerable to disability than more wealthy people (WHO and WB, 2011b:8). Second, there is an indication that people with disabilities and their families face high costs for medical care, support, treatment and for assistive devices. These extra expenses, not present in families without disability, may lead to higher rates of poverty (ibid., 11). A gap exists between policy and practice regarding disability, and an example is the non-inclusion of disability in the Millennium Development Goals, its targets or indicators (UN, 2013a:1; 2013c:2). Neglecting disability when addressing development has had effects for PWD and their families and has also impacted achievements of development goals negatively (UN, 2013a:2). This is acknowledged by world leaders, and preparatory discussions for the coming Sustainable Development Goals highlight the importance of involvement of persons with disability for sustainable development (UN, 2013c:3).

## 1.2 AIM AND RESEARCH QUESTION

This study intends to build on the existing knowledge about having a CWD in an east African setting, through the eyes of parents of CWD living in Dar es Salaam, Tanzania. The aim is to explore the experiences of parents and how their lives are impacted by having a CWD. Parents' perceptions and experiences of having a CWD do not stand alone, as the influences affecting their perception originate from multiple levels in society (Algood et al., 2013:133). Therefore, an adapted version of ecological theory (McLeroy et al. 1988), which divides society in four levels<sup>1</sup>, will serve as the structure for analyzing parents' perceptions of having a CWD. Since their experiences are embedded within society in which they live, parents' perceptions of the reactions and support from surrounding society will be investigated. This forms the research question and its sub-questions:

*How do parents, living in Dar es Salaam, Tanzania, perceive having a child with disability?*

- What challenges and related coping strategies do parents describe?
- How do people relate to the parents and their child?

To answer the research question, this study starts with a background on disability, specifically in the Tanzanian setting. Thereafter a review of previous research on parents' experience of raising a CWD follows. The theoretical framework and the concepts of coping, stigma, marginalization and normalization are discussed followed by the methodology of the study.

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<sup>1</sup> The structural, community, relational and individual level.

The analysis of parents' perception of having a CWD forms the main body of the study, and is structured according to the ecological theory. The theoretical concepts will be the line of argument through the discussion. Conclusions including suggestions on further research end the study.

## 2. DISABILITY CONTEXTUALIZED

To capture perceptions of the parents of CWD, there is a need to outline what disability implies. Many people have an understanding of what disability is, often illustrated by a person in a wheelchair (WHO and WB, 2011a:7), which is somewhat different from the understanding of found in academia. This section starts with a discussion of what lies behind the term disability followed by a commonly used definition. Thereafter, prevalence and magnitude as well as legislation surrounding disability, internationally and within the Tanzanian context is outlined.

### 2.1 DEFINING DISABILITY

Disability has historically been seen through the eyes of medical science in the context of pathology and impairment (Bricout et al., 2004:48). Later on, a social model of disability emerged from the disability rights movement stating that individuals are not disabled by impairments, but through disabling barriers in society (Oliver, 2013). This implies that disability does not only need individual medical treatment, but changes in social society are also required (Siebers, 2011:73). Disability is de-individualized and seen as a collective responsibility of society (Llewellyn and Hogan, 2000:159). A discussion beyond the social model of disability is present and often referred to as the ecological model of disability, (Altman, 2001:116-118) described by Devlieger et al. (2003) as environmental perspectives and individual aspects embedded within the lived culture.

The International Classification of Functioning, Disability and Health (ICF), a WHO framework officially approved by all member states<sup>2</sup> in 2001 (WHO, 2013) sees disability as: “an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)” (WHO, 2001:213). Influenced by the ICF, Tanzanian's PDA defines a person with disability as “a person with a physical, intellectual, sensory or mental impairment and whose functional

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<sup>2</sup> Tanzania is one of the member states.

capacity is limited by encountering attitudinal, environmental and institutional barriers” (Persons with Disabilities Act 2010:9). Definition of disability in this study departs from the description by the PDA and adds the broader ecological perspective of disability.

## 2.2 MAGNITUDE AND LEGISLATION

Tanzania, an east African country with a population around 45 million (NBS, 2013), and a Gross National Income per capita of \$570 USD, is considered a low income country (WB, 2014). To measure disability is complicated due to different definitions of disability, methods of data collection and questionnaire design, giving that the prevalence of disability among only children in Tanzania is most likely not known (UNICEF, 2013:3). However, the Tanzanian National Bureau of Statistic (NBS) estimates that 7.8 percent of the Tanzanian population above seven years has some form of disability. Among the rural population the prevalence of disabilities is 8.3 percent compared to 6.3 percent in urban areas. Out of the children 0-14 years old that live with a disability, 49 percent were born with the disability and 33 percent acquired their disability before the age of four years (NBS, 2010:89-91). Globally, an estimated five percent of children under 15 years old live with disability, for people above 15 years old, the corresponding number is around 15 percent, (WHO and WB, 2011b:8). People who care for individuals with disability are many more, around 25 percent (Cameron et al. 2005:269; WHO, 2001:3).

Tanzania made early national commitments to the rights of PWD through policies, starting from 1981 (MoLYDS, 2004:1). The PDA, which builds on the United Nations Convention of the Rights of Persons with Disabilities (2006), is the latest policy with the purpose; “to make provisions for the health care, social support, accessibility, rehabilitation, education, and vocational training, communication, employment or work protection and promotion of basic rights for the persons with disabilities and to provide for related matters” (Persons with Disabilities Act, 2010:5). The PDA also emphasizes the importance of families surrounding PWD and states that entire families should be supported by committees on different political levels (ibid., 47-48). The act also declares that counselling should be offered to parents, guardians and relatives of PWD “for the purpose of reducing or removing the degree of stigma among them” (ibid., 20). Even though advances of both international and national frameworks for disability are seen, a gap between policy and practice seems to exist both internationally and in the Tanzanian context (UN, 2013a:1-3 and Aldersey et al., 2011). An assessment found that many ministerial departments in Tanzania are not aware of the existing

laws and policies related to disability needs and rights, even fewer follow and implement them (Shivyawata and MyRight, 2013).

### 3. PREVIOUS RESEARCH

The area of disability studies, under which this study falls, is extensively discussed in the literature, often connected to the individual with disability and in interaction with surrounding society. Research also exists regarding parents' situation, in relation to the child's needs of specific services, although, parents may not be the main focus of the studies (Waldman et al. 2010:619). Studies that explore parents' perceptions of challenges, coping strategies and their experiences of caring for a CWD, are many and have for long been present in the academia (Green, 2007:150). According to my review, most of the studies are conducted in European or northern American settings. However, in the last decade studies in African contexts have been published, although few compared to the amount of European and American studies on the topic.

A literature review by Vandermindeln (2010) concludes that parental stress is natural and a part of having children. They also found that parental stress in the United States was significantly higher among parents of CWD, than among parents of children without disabilities. Graungaard and Skov (2006:298) looked at parents who received a CWD in Denmark and their coping strategies. They distinguished between problem focused coping, such as collecting information, learning skills, checking the health care, looking for alternative medicine and training options; and emotion focused coping such as retaining hope, creating future images, ignoring the seriousness of the condition, and seeking social support (ibid., 300). They concluded that finding effective coping strategies greatly reduced parents' emotional stress (ibid., 305).

A few studies have however been carried out in sub-Saharan settings. Weldeab and Opdal (2008) found that parents of children with intellectual disabilities in Ethiopia face emotional, social, economic and material challenges in raising their child. Gona et al. (2010) saw that parents of CWD, living in a poor rural setting in Kenya, experience challenges as emotional distress, fear for the future and stress. This catalyzed learning of new skills and looking for external support. Spirituality and sharing of experiences were coping strategies seen to create emotional stability. Hartley et al. (2005) did a study among Ugandan parents of CWD investigating their coping strategies and found challenges mainly concerned the burden of

care, poverty, the impact of the child's disability, communication problems and lack of knowledge. They also saw a heavy burden on usually one or two female caregivers, lacking support from the extended family. Coping strategies found were constant search for a cure, seeking of social, physical and material support from family and disability organizations. Turning to God and spiritual leaders was also described as a strategy for coping. McNally and Mannan (2013) looked at parent's perception of caring for a CWD in northern Tanzania. They focused mainly on challenges parents faced and distinguished between objective challenges; demand for care, financial challenges and the issues of employment for caregivers, and subjective challenges in terms of stigma, isolation and shame. Needs of financial help and supplies were identified. The study touched slightly on coping strategies and mentioned beliefs in God and prayers as well as receiving support in the caretaking from surrounding family and neighbors.

The experience of being a parent of CWD studied in an Australian setting found that caring for children with cerebral palsy affected parents' physical and social well-being, their freedom and independency as well as the financial stability of the family (Davis et al., 2009). Changes in the social life, higher levels of frustration and general dissatisfaction with the life situation were found among Israeli parents of CWD (Heiman, 2002:159). Much research has emphasised the emotional distress connected to raising a CWD, with less focus on the negative consequences of stigma and sociocultural constraints faced by many parents (Green, 2007:161). This is confirmed by a Canadian study finding a striving towards greater inclusion and tolerance for parents themselves and their children (Goddard et al., 2000:285). Mbwilo et al. (2010:7), who have studied parents of children and adolescents with mental disabilities in Tanzania, found discrimination against the families. Stigma and isolation were also expressed by parents of CWD in northern Tanzania (McNally and Mannan, 2013). Ryan and Runswick-Cole (2008:199) reviewed how mothers to CWD are portrayed in the disability literature and found them often marginalized in society and argues that mothers experience disablism<sup>3</sup> even if they often are not disabled. A literature review on marital impact due to raising a CWD saw that some studies pointed to significantly higher divorce rates in families having a CWD, than in other families, however no clear conclusions could be drawn about the causality. Nevertheless, disability of a child can cause damage to the parent's marital life, as it impacts the organization of the family (Kendek and Merrick, 2003:746).

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<sup>3</sup> Discrimination against PWD.

An ecological perspective has been used in disability studies, where factors affecting disability are seen in a dynamic system with interrelations between individual and environmental factors (Bricout et al., 2004; Llewellyn and Hogan, 2000:160). The ideas are developed in the context of physiology and human development departing from Bronfenbrenner's (1979) theory of ecology of human development. He describes four levels in which human development is embedded; the micro-, meso-, exo-, and macro- systems, where each system influences the individual persons' development as well as the other systems. The challenge is to distinguish between the different systems and to be aware that the theory does not provide predictions, but rather indicates general relationships (Bricout et al., 2004:55). Criticism has also arisen when using the theory in practice as all systems impact the individual, which makes it difficult to focus attention for both research and intervention (Ferguson, 2001:388).

The theory has been further developed by Bronfenbrenner himself (Tudge et al., 2009:198) and by other authors within different fields (Fougeyrollas and Beauregard, 2001:173). Ideas from the ecological theory have also been used when studying families with CWD, to illustrate influences and interrelatedness between the levels in the ecological levels, and their impact on family life (Ferguson, 2001:388). Algood et al. (2013) contend that parents' perceptions of raising a CWD are multifaceted as they do not operate in isolation, but are influenced by the contexts, communities and wider society in which they live (Algood et al., 2013:127). The clearly outlined ecological theory by McLeroy et al. (1988), originated in Bronfenbrenner's theory, assumes that social environmental factors affect the individual and that support of the individual is essential for implementing changes in the social environment.

This study uses the ecological theory by McLeroy et al (1988) and empirical findings from studies in countries around the world as a starting point. The theoretical contribution is to use the ecological theory for structuring parents' individual perceptions of having a CWD. The approach is different to other studies in using the theory for exploring *perceptions* of having a CWD and in focusing on the *individual* parent rather than on the family or the CWD. The empirical contributions are the focus on the individual parent's perceptions, the contextual setting of Dar es Salaam, as well as integration of the concepts of stigma, marginalization and normalization to understand parents' perceptions of having a CWD.

## 4. THEORY

### 4.1 THE ECOLOGICAL THEORY

The structural framework departs from McLeroy's et al. (1988) ecological theory, developed for health promotion interventions. The empirical material guided the adjustment of the theory. This section describes the adapted version and its heritage.

Parents' perceptions of having a CWD in relation to society where they live are analyzed on four levels. The outermost circle (see Figure 1) is called the public policy level by McLeroy et al. (1988:355) and refers to the state and national laws and policies. In this study the level is called the *structural level* to capture the political and macro-social arrangements in society and the analysis mainly describes parents' perspective on the government's actions related to having a CWD. Thereafter the *community level* is situated, which is a merging of the organizational factors and community factors in McLeroy's et al. theory. The organizational factors relate to formal organizational settings such as schools and worksites and social, instances such as voluntary organizations and neighborhoods (ibid.,360). The community factors have three meanings; mediating structures, which relates to informal social networks such as churches, stores and community organizations; relationships between organizations and groups within a defined area; and in geographical terms (ibid., 363). Organizational and community factors are interrelated and the theory has been criticized for the issues of separating aspects that belongs to both levels (Winch, 2012:11). Together with the suitability for this study the two factors were merged into one called the community level. As healthcare not is included in any of the levels in McLeroy's et al. theory, the decision to situate it within the community level was made. However, as will be seen in the analysis, it also relates to the structural level. The found themes for the community level therefore refer to healthcare and education for the child, parents' working situation and social interactions and support received from neighbors and extended family. The *relational level* (named interpersonal processes by McLeroy et al.) outlines formal and informal social networks and support systems including the family, workmates and networks of friends (McLeroy et al. 1988:355). The relational level in this study refers to the relation with the CWD as well as with the whole family and the household situation. Relationships with friends and workmates are all placed at the community level due to the hardships of separating relations with friends (interpersonal processes (ibid.)) from relations with neighbors and workmates (organizational factors (ibid.,360)) in the empirical material. The innermost level, intrapersonal factors relates to the individuals characteristics such as knowledge, attitudes, beliefs and self-concept (ibid.,350).

This level is here called the *individual level* and covers mostly the parents' feelings related to having a CWD. Most focus in the analysis is on the community, relational and individual levels, as these are the areas most emphasized by the parents during the interviews and are believed to impact perceptions of having a CWD.

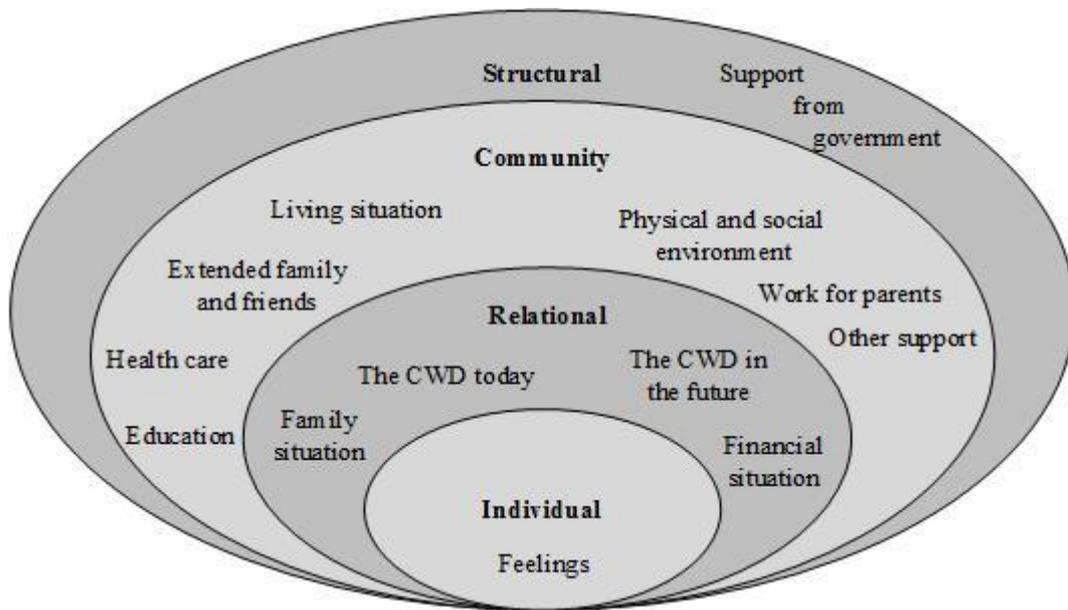


Figure 1: Factors found in the empirical material that impact parents perception of having a CWD, structured according to the adapted ecological theory.

The adapted ecological theory differs from the theory by McLeroy et al., hence this study is explorative in character. However, as neither the original theory by Bronfenbrenner nor the developed version by McLeroy was generated for studying perceptions or disability, the careful adaption for the suitability of this study may introduce a new area of usage for the ecological theory.

#### 4.2 THEORETICAL CONCEPTS

To further explore and understand parents' situation of having a CWD, four theoretical concepts have been identified. Coping strategies are used to comprehend the challenges faced and in what way parents deal with them in their life. To base the analysis only on concepts of coping, as has been done in similar studies in African contexts (Gona et al., 2010; Hartley et al., 2005 and McNally and Mannan, 20013) was insufficient to understand parents' perceptions of having a CWD. Stigma, marginalization and normalization were a line of argument when parents described their perception of having a CWD, and are therefore used to crystalize the parents' perceptions of having a CWD.

#### 4.2.1 COPING

Coping is seen as “a stabilizing factor that can help individuals maintain psychosocial adaptation during stressful periods”, which includes efforts to reduce or eliminate stressful conditions and its associated emotional distress (Holahan et al., 1996:25). The literature regarding coping strategies is extensive and advanced with a psychological focus, demanding knowledge and experience for a thorough assessment (Parker and Endler, 1996:8-12). However, two broad dimensions of coping were defined early and have continued to be central in the research; *problem focused* coping, which involves strategies to solve, re-conceptualize or minimize the effect of a stressful situation or a problem. The *emotion focused* coping dimension relates to strategies that regulates the emotional response to the problem (Parker and Endler, 1996:9). Gona et al. (2010:179) who investigated coping strategies among parents of CWD in Kenya found problem focused coping strategies to be learning new skills, search for cure and external support. For emotion focused coping they detected belief in God and sharing of experiences. The division of coping strategies into these two broad categories has been proven too simplistic by psychologists, and more advanced models of categorization exist (Carver et al., 1989:267). However, for simplicity, in this study coping strategies will be divided into problem and emotion oriented, which will be discussed within each level in the structural framework. To clarify, this study does not engage in a discussion on the effectiveness on the described coping strategies.

#### 4.2.2 STIGMA

The concept of stigma will be used to understand why and how parents of CWD perceive reactions from their surroundings. Sociologists suggest that individuals with disability can experience stigma (Earle, 2003:5), described by the influential sociologist Erving Goffman (1965:3) as: “[t]he phenomenon whereby an individual with an attribute which is deeply discredited by his/her society is rejected as a result of the attribute. Stigma is a process by which the reaction of others spoils normal identity”. Stigma can also be contagious, as outlined term “courtesy stigma”, which is the “tendency for stigma to spread from the stigmatized individual to his close connections” (Goffman, 1965:30). Barnes et al. (1999) confirm that not only the individual with the disability experiences stigmatization – it can affect the individual’s entire family. Two types of stigma associated with individuals are identified; *discrediting* conditions, which are obvious to others and often has a physical attribute, and *discreditable* conditions, which usually are not visible or can be easily covered. In both types of stigma an individual possesses a trait that attracts attention and turns others away. These conditions can be a person’s “master-status”, shown as whatever the individual

is or has accomplished, the condition will still be the first thing that others see (Goffman, 1965:4).

#### 4.2.3 MARGINALIZATION

Stigma, attached to individuals with disabilities and their families, can result in marginalization, which constrains access to resources and opportunities in society, according to a study in Ghana (Baffoe, 2013:187). This implies the need to include the broader concept of marginalization to this study.

Marginalization can be seen as a process of moving to the side, as a consequence of not accepting the recognized rules of operation. The rules, defined within social society, are built up by norms. Those rejecting or being rejected from these norms, are vulnerable to be drawn into marginalization (Ravaud and Stiker, 2001:506-507). Consequences are low control over one's own life and the available resources, negative public attitudes and humiliation from others. This can affect opportunities to make social contributions, which in turn influence self-confidence and self-esteem, leading to limited opportunities for meeting others and in severe states leads to isolation (Ravaud and Stiker, 2001:506-507). Burton and Kagan (2003:6) see this correlation as a *vicious circle* where the lack of positive supportive relationships prevents participation in local life, leading to further isolation. In involuntary marginalization, a person's selfhood and humanity are threatened, and ignoring it may lead to discrimination, which further on undermines the essence of humanity (Burton and Kagan, 2003:16; Ravaud and Stiker, 2001:507).

#### 4.2.4 NORMALIZATION

To avoid marginalization individuals with disabilities and their surrounding families are often prone to reducing deviance and to "act as others", a concept related to as normalization (Darling, 2003:882 and Ravaud and Stiker, 2001:506-507). The underlying values are basic and involve all human beings' right to be loved, have a family, and have intimate relations as well as to be productive, educated and to have a purposeful life with good quality (Bronston, 1974:492). The concept of normalization emerged in the 1970's and has been widely discussed in academia, hence finding one single definition is difficult. However, common characters are shared (Culham and Nind, 2003:67) and refer to striving for a life as close as possible to that of an "average" person, matched for sex, age and culture, and still maintaining personal behaviors and characteristics. This refers to all areas of life, such as education, housing, working and leisure conditions, and includes recognition of legal and human rights that apply to all citizens (Darling, 2003:882; Culham and Nind, 2003:67). Originally the

model of normalization focused on persons' with intellectual disability, and has expanded to involve all undervalued and deviant groups in society (Wolfensberger, 1985, cited in Culham and Nind, 2003:67). Bronston (1974:493) states that there are three rationales behind the concept of normalization; all people will be perceived and treated as human beings, as citizens, and as persons that develop, adapt and give response to their surrounding environment.

## 5. METHODOLOGY

### 5.1 RESEARCH APPROACH

A qualitative approach influenced by constructionism was undertaken as a way of understanding the phenomenon of being a parent of a CWD (cf. Bryman, 2008:19). The approach is emic, and seeking to *explore* the parents' perceptions and view of their reality. Constructionism is essential concept in sociology, built into the social model of disability and central in the ecological theory. The ontology indicates that social phenomena are generated through social interactions (Bryman, 2008:19) and have been used to understand the perception of the participants rather than to explain it. To dig deeper into the underlying reasons for the perceptions described by the parents, an interpretivism standpoint was used (cf. Bryman, 2008:15). This has fueled questions like why parents feel stigmatized in society and how the actions and opinions of the stigmatizing towards the stigmatized can be understood.

As the aim of the study was to *explore* as well as to *understand* deeper perspectives of people in a given time, situation, and context, a case study was applied (Bryman, 2008:54; Creswell, 2007:73-75; 2009:65). The case is structured around marginalization where the unit of analysis as well as the boundaries of the case, were parents of CWD living in Dar es Salaam, Tanzania. Noteworthy, the study does not aim for generalizable or transferable findings applicable to other contexts (Bryman, 2008:57 and Denscombe, 2003: 36-37). Data generation and primary data analysis were undertaken simultaneously and during the stage of writing I went back and forth between the empirical and theoretical material whereby the study took on an abductive approach (Blaikie, 2010:156).

### 5.2 RESEARCH PARTICIPANTS: IDENTIFICATION AND DATA GENERATION

Primary data were obtained through focus group discussions (FGD) and semi-structured individual interviews. FGD is a tool to explore attitudes, perceptions, feelings and ideas, (Bryman, 2008:489) as well as a good instrument to learn more about a specific topic (Blank, 2013). However, FGDs have been criticized for generating biased results if one or a few of

the participants are dominant or take the lead in the discussion, which is a weakness of the method. Even the moderator may impact the group through the way questions are asked (Betts et al., 1996:280). To limit these weaknesses, the moderator was well informed and aimed at equal involvement of the participants through directing questions when needed. Semi-structured interviews can be time-consuming (Denscombe, 2003:111) and the outcome depends on the skills of the interviewer, however interviews were chosen as they use open ended questions allowing the participant to speak broadly around the topic and the researcher to probe and create a dialogue with the participant (May, 2011:134), which was seen as beneficial for understanding parents' situation. Secondary data, applied to frame the primary data, contained academic articles, books and reports from UN-organizations as well as from the Tanzanian government.

The plan was to start off with FGD to learn about the topic and to test the relevance of the study (Blank, 2013). Thereafter semi-structured individual interviews should have followed, building on the knowledge gained in the FGD. Due to issues in gathering all invited parents for a FGD at a specific time, a few individual interviews were done between the first and second FGD. This affected the study as there was no time for analyzing findings from the first FGD before individual interviews were conducted. The consequence was thinner data generated from the individual interviews conducted early in the process. However, it gave me opportunity to practice my interview skills, and as most interviews were done through an interpreter, the situation built up collaboration with my interpreter, which was found important and beneficial for the study. The individual interviews at the end of the data generation procedure had richer data, as the interview guide had been sharpened (cf. May, 2002:119) and as I and the interpreter had developed our skills and collaboration.

### *5.2.1 IDENTIFICATION STRATEGY*

Sampling of participants was done purposively through mainly one key gatekeeper followed by snowball sampling (Bryman, 2008:458). The gatekeeper provided contacts to organizations and schools for CWD, which led to the participants. Inclusion criteria were set to be parents of a CWD. An age criteria for the child being at least three years old was set to select parents that have, somehow, passed the initial trauma related to receiving a CWD (Falik, 1995 and Heiman, 2002:160) and who have started to get an everyday life in caring for their child. No limitation was made to a specific type of disability as the experience of having a CWD not is dependent on the type of disability but rather on other external factors surrounding the parent (Breslau et al., 1982:682; Resch et al., 2012:70). Many participants

were interviewed without their children, which in combination with most parents stating their children did not have a formal diagnosis, resulted in relying on the parents' self-identification as caregivers for a CWD. However, there was no reason doubting that any of the participants not being within the inclusion criteria was found.

As Dar es Salaam is the largest town in Tanzania, it also hosts an overrepresentation of special schools and disability organizations, compared to Tanzania as a whole. This was an important enabling sampling factor for the study, and at the same time, it did not give a broader picture of the situation in the country as such. The identification of participants was done first through organizations for PWD, willing to speak to a foreigner and who had the ability to schedule the interview on short notice. This affected the material generated as some participants were very active in these organizations and used to talk about their issues and to lobby for disability. Other participants, found through the following snowball sampling, were noticeably shyer speaking to a foreigner and not used to talking about their situation. This provided a mixture of individuals and backgrounds of the participants, which was seen beneficial for the study.

### *5.2.2 DATA OBTAINING AND THE PARTICIPANTS*

I met a total of 31 parents in Dar es Salaam between 27<sup>th</sup> of November 2013 and 19<sup>th</sup> of January 2014. The first FGD had four participants, who all had children at the same school where the FGD was conducted, and the interview lasted 1 hour 45 minutes. The second FGD had six participants, all members of the same organization for parents with CWD; conducted in the office of a disability organization and lasted 2 hours 15 minutes. Detailed characteristics for the participants in the FGD are found in table 1 and the interview guide used is presented in appendix 1.

The semi-structured interviews were conducted in restaurants, parents' homes and schools of their children. Except for the interviews conducted in schools, the setting of the interviews was chosen by the parents for their convenience (Creswell, 2009:64). This was done to make the participants feel relaxed and have an advantage as they were familiar with the environment, as the interview itself was a setup and not corresponding to a natural setting (ibid., 138). The interviews lasted between 30 and 75 minutes. In one of the interviews both parents of the child participated. Detailed characteristics for the participants are found in table 2 and the questionnaire used is accessible in appendix 2.

Table 1: Characteristics of focus group participants.

Variables	N = 10
<b>Gender</b>	
Female	6
Male	4
<b>Relation to child</b>	
Parent	8
Sibling	1
Grandmother	1
<b>Characteristics of child's disability*</b>	
Mental impairment	4
Hearing and sight impairment	5
Mental impairment and deaf	1

\*when no official diagnosis was stated, the characteristics are according to parents descriptions according to parents descriptions.

Table 2: Characteristics of individual interview participants.

Variables	N = 21*
<b>Gender</b>	
Female	13
Male	8
<b>Relation to child</b>	
Parent	15
Aunt/Uncle	2
Grandmother	2
Sibling	2
<b>Characteristics of child's disability**</b>	
Mental impairment	7
Cerebral Paralysis	6
Hydrocephalous	3
Spinal Bifida	2
Physical and mental impairment	1
Chronic degrading disease	1

\* one interview contained the child's mother and father

\*\* when no official diagnosis was stated, the characteristics are according to parents descriptions according to parents descriptions.

Verbal informed consent was collected from all participants prior to each interview and their names were not collected in order to ensure confidentiality (Mikkelsen, 1995:337-338). I tried to keep the places as secluded as possible for the participants to be able to speak freely on the topic (May, 2002:214-215). The interviews were all audio taped and notes were taken (Creswell, 2009:140) by both me and the interpreter, which were used to capture tensions and feelings of the participants, and have been used as unstructured observations (Bryman, 2008:257). Some interference interrupted most interviews, such as people entering the interview session and heavy rains when interviewing in schools with iron roofs, which caused noise, this may have affected the interviews negatively. However, through the notes taken during the interviews regarding the participants' reactions to the interference, it seemed not as disturbing for the participants as for me as a researcher.

When generating the interview guide, ideas and concept used in other studies (Gona et al., 2010; Hartley et al., 2005; McNally and Mannan, 2013) were considered to add credibility to the study (Bryman, 2008:34). Judging from observations and information volunteered, the participants represented a variety of socioeconomic groups; however the larger part were from lower socioeconomic backgrounds. This could be inferred through many of the participants expressed concerns of not having enough money for the basic needs.

### 5.3 INTERPRETATION AND TRANSCRIPTION

The language spoken by the participants was Swahili, in which I have limited knowledge. This resulted in the use of an interpreter<sup>4</sup> for the interviews and the same interpreter was consulted during the whole study. Two semi-structured interviews were conducted without interpretation, as those participants were confident in speaking English.

Interpretation of the interview guides was done by a second person experienced in translation. The importance of using a simple and everyday language was emphasized (Esposito, 2001:572). The translation was cross-validated (Kvale, 1997) by my interpreter, which resulted in changes of a few words used in the Swahili version. For FGDs, when the researcher does not speak the language of the participants, Esposito (2011:573) suggests that a trained facilitator lead the FGD while a translator simultaneously translate to the researcher, who can direct the discussion if needed. This was not possible, and the second best approach was undertaken; relying completely on the facilitator (ibid.). The facilitator (my interpreter) had experience in conducting FGD and was informed about the study and the methodology of FGD prior to the discussions. During the FGD, conducted in Swahili, small pauses were made to brief me, which gave me some, but limited, control over the data generation.

Translating and transcribing of the audio-taped interviews conducted in Swahili were done by the same person interpreting the interviews. Meaning based translation (Esposito, 2001:572) was emphasized and the full recordings were transcribed and translated in one simultaneous step. The first half of the interviews conducted in Swahili were transcribed within a week, for the second half, transcribing was done within two weeks after the interviews, due to the workload of the transcriber. The two interviews conducted in English were transcribed word by word by me within a few days after the interviews.

### 5.4 METHOD OF ANALYSIS

The thematic matrix based analysis method Framework<sup>5</sup> (Ritchie et al., 2003:219), was used to analyze the material. The tool is rigorous and systematic (Ward et al, 2013:2429), has clear stages of procedures including data management, descriptive accounts and explanatory accounts (Ritchie et al., 2003:17), which is rare in thematic analysis (Bryman, 2008:555). Framework analysis was chosen as it is used for both individual and focus-group interviews (Rabiee, 2004:657), and allows themes to develop from the research questions and from the

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<sup>4</sup> The interpreter was not a professional interpreter; however she was fluent in both Swahili and English.

<sup>5</sup> The Framework method is developed at the National Center for Social Research in the United Kingdom (Ritchie et al, 2003:219).

narratives of the participants (Dixon-Woods, 2011:39). The tool emphasizes the importance of carefulness when synthesizing the data, which according to Bryman (2008:553) can reduce the issue of fragmentation of the narratives, a common critique of qualitative analysis tools. Although the Framework analysis has received critique of being time consuming (Ward et al., 2013:2428), this is the case for most qualitative data analysis methods.

*Data management* initiated the analysis with familiarization of the material and development of a thematic framework. Initial themes and concepts located during familiarization were grouped under broader categories forming an index, thereafter applied to the whole raw material. Charting was undertaken, where the data were synthesized and sorted into a matrix where each interview got its own row and each theme had a column. The software QDA Miner Light v.1.2.2 assisted the indexing and charting. In the *descriptive account*, detection, categorization and classification of the sorted data were undertaken to generate descriptions and identify phenomena. In the last stage of *explanatory accounts* the material was viewed on a higher stage to find linkages between phenomena and analyzing the findings in a broader theoretical perspective (cf. Ritchie et al., 2003:217-262).

## 5.5 TRUSTWORTHINESS OF THE STUDY

The chosen methods for this study (Bryman, 2008; Creswell, 2007; 2009; Guba, 1981; Shenton, 2004; and others) were considered to ensure that the research was clearly defined, appropriate and that the conclusions drawn were in line with reality. Triangulation in terms of comparing FGD and interviews ensures consistency of the data, and enhance the dependability of the study (Shenton, 2004:71).

The fact that most of the information was generated through an interpreter, adds a disadvantage to the study's credibility (Esposito, 2001:568). The information and apprehension that I missed, by not being able to understand the participants initial ways of expression, can be supposed to have reduced the depth of the interviews as well as my own understanding of the parents. However, contact with most parents would not have been possible without the interpreter, and who also helped me understand common Tanzanian practices and traditions, important for the analysis. My own predisposition can be seen as a threat to the credibility of the study (Shenton, 2004: 72 and Guba, 1981:81), as my preconceptions regarding disability, theory and the social climate I was about to face in Dar es Salaam had to be reevaluated. I had to take several steps back to give room for the participants', and let their perceptions of their own life be as visible as possible in the analysis.

The participants had different perceptions of me; a potential money provider, a psychologist, a person who knows everything or a scary European, which most likely affected the interview in either a positive or negative way.

Transferability relates to the applicability of the study and to what extent the study has applicability in other contexts (Guba, 1981:79-81). Other studies on similar topics conducted in an East African setting (Gona et al., 2010; Hartley et al., 2005:169; McNally and Mannan, 2013), have been influential in designing questionnaires and during analysis of empirical material. However, the context of Dar es Salaam is different from these studies, and the study does not aim to provide transferability, although some findings and conclusions may apply to similar contexts (Guba, 1981:81).

## 6. ANALYSIS

The analysis is divided into four parts according to the adapted ecological theory. The described challenges outline the structure, followed by a discussion regarding coping strategies and how surrounding people relate to the parents. The first section relates to structural level of the ecological theory. The second and third section contains the community and relational levels. Parents' feelings related to having a CWD discusses in the last section, the individual level. Throughout the analysis, parents' perceptions are analysed through the concepts of stigma, marginalization and normalization.

### 6.1 STRUCTURAL LEVEL

At the structural level challenges in the form of insufficient support from the government were expressed by the parents and the relating emotion oriented coping strategy was blaming others.

Parents expressed an expectation that the government should bring different kinds of support to families with disabilities. A few were aware of actions taken by the government, although most parents saw little support from the state. An area where governmental support was requested was more schools adjusted for children with special need; finding a suitable school willing to enroll her daughter is described by Mama Alice:

*“when she was at age 8, the normal school refused to admit her, then she stayed at home for some time until one day her elder sister found a school for children with disability and it's here [primary school] where she is right now, however when she was young I brought her here and they denied her admission because they saw that she was fine like other normal children and*

*suggested to take her to normal schools...but this time they accepted her for first two weeks to check out if she suits the school, later after that they accepted her” (Mama Alice, 20).*

This was a common case, and children often attended several different primary schools during their childhood. Parents, of children with multiple disabilities, stated that none of the schools they had contacted were willing to enroll their child, indicating a lack of suitable schools for this group. There was also a scarce availability of secondary and vocational training schools accepting CWD. Discrimination in and restricted access to education are more common among CWD than for other children (UNICEF, 2008), which is in line with the findings in this study. The parents also requested a clearer curriculum for children with special needs and higher ratios of teachers educated to teach CWD. The government is aware of these problems, and states that the lack of unsuitable curriculums and flawed education for teachers concerning CWD, negatively affect the children (MoLYDS, 2004:5). Emphasis on the importance of education and priority for enrollment will be given to CWD, “[d]espite this commitment the educational system is inaccessible to children with disabilities” (ibid., 15). The quality of education was discussed as low by a few parents, and could be perceived when parents of older children described challenges for them finding a job, even though they had completed school.

Other desires were free health care, physiotherapy and for various aids to be made available. Requested support related to the child’s adulthood was; to find relevant jobs and organization of caregiving for the child when parents themselves became old or had passed away. Hardships in attaining governmental financial support for parents of CWD was seen and sometimes expressed as completely absent.

*“maybe someday, sometimes... things might change for the better, we get a minister that have undergone some experiences of such nature [disability], who might do something, I don't know, but the country is rich, its just a matter of strategy, what you want to do, prioritize” (Grandma Samuel, 7<sup>6</sup>)*

Grandma Samuel’s thoughts express lack of governmental support. This is confirmed by Aldersey et al. (2011) who discusses the government’s flawed ability to operationalize disability laws and policies. There could also be an information gap, where parents do not know about their rights and the services available. As many employees at ministerial departments are not aware of existing laws and policies related to disability (Shivyawata and

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<sup>6</sup> In Tanzania, parents are usually called by the name of their child and not by their own name, for example a father with a son called Lucas is called “Baba Lucas” and the mother would be “Mama Lucas”. The same system is applied here for identifying the different parents interviewed, although their children’s names have been changed to ensure confidentiality. The number after the name refers to the child’s age.

MyRight, 2013), it is likely that there is both a gap in operationalization and in informing the beneficiaries of their rights and available service.

Some parents seemed to blame their struggles on the government. This has been discussed as a coping strategy among persons in other vulnerable situations, such as unemployment (Erasmus, 1999:62). The strategy of blaming someone else, a common emotion oriented strategy (Nazemi, 2007), could in this case also be a strategy of hiding the original problem, whereby the real coping strategy of the parents could be viewed as differentiation and revulsion from the problem, as well an emotion oriented coping strategy.

## 6.2 COMMUNITY LEVEL

The areas impacting parents' perceptions related to the community level, and which will be discussed here are health care and education for the child, the work situation for the parents, the physical and social environment in society, the neighbourhood in which they live and support from extended family and others. Related problem oriented coping strategies were to strive for treatment and education, learning new skills, avoiding insecure environments, educating others, relocating and staying close to the child. Emotion oriented strategies were: acceptance, turning to God<sup>7</sup> and sharing of experience.

### 6.2.1 HEALTH CARE

All parents had been in contact with medical professionals at some point concerning their child. Due to the disability the children had a continued need for frequent health check-ups, medical treatment and physiotherapy. Parents experienced issues of finding reliable health care professionals knowledgeable about disabilities. This led to redirections to several different hospitals before finding treatment for the child. Parents frequently discussed errors in surgeries, receiving wrong diagnosis and treatment, negative effects of medication and medication errors. This resulted in unnecessary suffering for the child, persistent damage, and in some cases caused or aggravated the child's disability. Many parents expressed hardships in financing the needed health care, medicines and related means of transportation. Regular physiotherapy was advised by health care professionals, for children with physical disabilities, and parents saw the importance of these exercises as the child made improvements. However, it was a challenge to find affordable, reliable, determined professionals, who saw the child, and could educate parents in how to perform the exercise. For parents with financial constraints, the child's participation in physiotherapy was often insufficient. When money

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<sup>7</sup> When the word God is used in the analysis, there is no association to a specific religion, as parents' religious belonging was not studied.

was available parents used this mean for assuring sufficient physiotherapy for their child, illustrated by Baba Leila;

*“But as a private case, I find the physiotherapist there at CCBRT<sup>8</sup> and pay her some extra money for the physiotherapy to be more effective and not to depend on one physiotherapy per week “(Baba Leila, 4).*

McNally and Mannan (2013), discussed similar demands for health care in Moshi, northern Tanzania. Kwesigabo and colleagues (2012) confirm the health care state described by the parents and call the situation in Tanzania a health system and work force crisis with severe shortage of trained healthcare professionals, aggravated by low motivation and poor morale of the staff, which inevitable negatively affects the patients.

A problem oriented coping strategy was persistent striving for good treatment for the child, through visiting several different health clinics and doctors. The other problem oriented coping strategy was learning new skills to ease financial constraints related to treatment, exemplified by learning how to conduct physiotherapy for the child. Others found means to reduce transportation costs or used alternative ways of funding checkups. Through Baba Michael we get insight into one parent’s reality:

*“I was carrying Michael on my back then going to Muhimbili hospital<sup>9</sup> by bicycle, it reached a point where I started selling home properties such as bicycle and so many other home assets in order to afford hospital services because I did not have any another sources of money... [This] is where my life status began to drop” (Baba Michael, 13).*

### 6.2.2 EDUCATION

Some challenges related to education were connected to the structural level, some are connected to the community level, and they can also be related to the relational level in terms of financial and time-constrains for parents, for the simplicity this section presents even factors related to the relational level.

Mkumbo (2008) discussed several barriers in accessing education for CWD in Tanzania; one of them was described as parents’ resistance to send their children to school. This seems not to be the case among the parents represented in this study. All parents discussed the value of education for their child and emphasized the importance of schools adjusted for their child’s need and developmental abilities. However, there were other challenges to education for CWD existed. Retention and attendance emerged as severe problems when the children were

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<sup>8</sup> A private funded hospital specializing in health care for people with disabilities.

<sup>9</sup> The national hospital in Dar es Salaam, government funded.

enrolled. Underlying reasons included high costs for school fees, transportation costs, time constrains for parents accompanying their children to school and the health condition of the child. This indicates that there were other factors than parents' resistance that affected the children's schooling. A few parents had kept their children at home in periods when the child was "too stubborn" to avoid disturbing the teachers. Through education some saw that the children received new knowledge like counting numbers, and other parents experienced learning of life skills such as hygiene and improved behavior. Several parents expressed the issue of repeating the same class over and over again as they saw stagnation in their child's development and requested clearer curriculum for children with special needs.

Parents with young children emphasized the need for education as the only solution for their children. However, parents with older children saw that even if their child had an education, and work experience, it was difficult for them to find a job. Parents experienced that people around them questioning them in taking their children to school. They saw it as waste of time and resources, as they did not believe the children could learn anything. This was discouraging for parents; however, *they* saw the benefit of education for their child. Aunt Simon, 6, expressed that "*bringing him to school makes him active like other children, that's why he likes to come to school*". Mama Andrea exemplified the continuous striving for the child's education; a problem oriented coping strategy fueled by parents' perception that even their child had the right to education and to have fun with their peers.

*She is in normal nursery school now, by begging so much to the teacher because the school doesn't accept children like Andrea, so I use to go and help doing cleaning of the school on Saturdays, however I had to pay... (Mama Andrea, 6).*

Parents' struggles for education for their child is evident, and the underlying motive seems to be the will to give the child a life as normal as possible, known as normalization, which is based on the premise that most people desire the same goals (Darling, 2003:882). In this case it is education. The elusive goal of normalization forces parents to overcome barriers through help from supportive teachers, compromises and inventive solutions (ibid.). An example is described by Mama Gloria:

*"She wears pampers<sup>10</sup> to avoid infection when going to the toilet [at school] [because she] use hands to climb stairs. That means she has to urinate in pampers like a baby and if it happens there is no pampers she does not go to school [...] She wears pampers because of the toilets... otherwise she is able put off panties" (Mama Gloria, 7).*

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<sup>10</sup> Referring to diapers.

Normalization is also seen as a goal in other areas; good medical care as described above and adequate financial resources and employment for one or both parents (Darling, 2003:882.). This will be discussed in the next section.

### 6.2.3 WORK SITUATION FOR THE PARENTS

Caring for a CWD has clear negative impact on parents' employment and family income (Heller et al., 2007:136). The underlying reason can be insufficient support in caregiving (Chou et al., 2012:260). In this study, financial challenges originated in issues of combining work with caring for the CWD. One mother with a permanent job was terminated, as a consequence of absence when her child was born. Mama Diana, 6, represents a commonly described reality:

*"I carried my daughter on my back when doing my small business, but the costumers reacted like they saw something awkward or became completely astonished, all these reactions really hurt me, so I decided to stay home and stop the business" (Mama Diana, 6).*

Due to stigma from society, Mama Diana and many other parents described marginalization as well as discrimination at the labor market as consequences of having a CWD. The lost opportunity of work was in this case not related to Mama Diana's inability to work but to how others saw her child. The norms and attitudes in society were the limiting factors (Peters, 2009:9) causing stigma, which in the end led to financial constraints for the family. Working parents also experienced challenges of being late to work or having to leave early to pick the child from school. Baba Leila, 4, had continued to work when Leila was born, although he missed investment opportunities and saw stagnation in his business. One mother described that she no longer was able to support her parents financially, which is traditionally expected, and this made her sad and her parents disappointed. A decreased income simultaneously of experiencing increased expenses related to their child, had severe implications and resulted in stress for the parents. This will be further discussed in the relational section.

### 6.2.4 PHYSICAL AND SOCIAL ENVIRONMENT

Parents described the physical and social environment in Dar es Salaam as challenging, insulting and even dangerous for CWD. Poor road quality and often absent side-walks led to issues of accessibility for those with vision impairments as well as physical impairments. On daladala<sup>11</sup>, issues of access existed in terms of physical accessibility of entering the bus and crowdedness. The social environment on the bus was another challenge, as some co-

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<sup>11</sup> Daladala is the term for busses operating in the public transportation system of Dar es Salaam.

passengers looked down on their children in a “*disgusting way*” (Mama Lucas, 9), stared, or gave negatively associated comments about the children. Mama Lea expands the discussion:

*[When I] carry Lea on the back while walking on streets you find most of people insisting on putting her down to walk by herself because they see as I am spoiling Lea by carrying her while she is old enough to walk, that happens even in daladala and I find it very difficult to tell everyone that my child has disability... so I remain internally hurt” (Mama Lea, 6).*

The children’s disability was discredited in society resulting in the CWD being rejected or set aside and stigmatized, a reality also discussed by Goffman (1965:3). Most likely, this affected the children themselves and it clearly affected their parents who often described the painfulness in receiving these comments, and lacking energy to explaining the physical appearance or the child’s deviant behaviour when involved with the community. An implication seen was avoiding being in the community as a problem solving coping strategy, which implied that both children and parents became isolated at different degrees. The other strategy was emotion oriented, and originated in acceptance as parents kept quiet and avoided getting into quarrels with others in the community, as exemplified by Mama Lea. In this context stigma and its consequences were not only experienced by the CWD, but also by the parents, indicating that social approval is contagious and affect the stigmatized individual’s family who has to “share some of the discredit”, and became affected by what Goffman calls courtesy stigma (Barnes and Mercer, 2010:48 and Goffman, 1965). Stigma and the feeling of distancing that it can result in were also present in the near-home environment, which is outlined in the next section.

### 6.2.5 LIVING SITUATION IN RELATION TO NEIGHBORS

In relatively deprived areas in Dar es Salaam it is common to live in crowded settings where toilet and kitchen are shared. This was difficult for parents of CWD as their children tend to run away, disturb neighbors or destroy their belongings. The opposite situation existed, that neighbors’ were a challenge for the parents and their child. Humiliation from neighbors towards the child was common; children were given bad names, as Grandma Samuel exemplifies, and were not allowed to play with children in the neighborhood, as their disability was believed to be contagious.

*“some neighbors who give him bad names, kibetembete<sup>12</sup> it is a lame person or a lame kid who cannot utilize his limbs and then the brain, well it is him, but I don’t want him to be called that name. It is a humiliation” (Grandma Samuel, 7).*

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<sup>12</sup> Swahili word.

Some children were beaten, chased or mistreated in other ways by neighbors due to their divergent behavior. Also parents, and more often mothers than fathers, told that they were insulted and received harsh comments due to their child's disability. A few parents got accused for causing the disability through mistreating their child. Others felt humiliated as no one would "assist to carry my child;<sup>13</sup> instead they were laughing at me, discussing me that I have borne a child with disability" (Mama Gloria, 7). Mama Gloria was treated differently; due to her child's disability she was denied the traditionally expected support, putting her in a marginalized position where she was humiliated (cf. Ravaud and Stiker, 2001:506).

*"you find that a person is just passing and you can hear them saying in that house there is a lady with disable child ... or you may find you are passing by a women's hair salon then they call you as you are a lady who has a disabled child instead of calling you by your child's name, its painful so you end up crying and canceling about the place you were heading to, so it's really difficult" (Mama Lea, 6).*

Mama Lea's "master-status", the first attribute that others saw and talked about (Goffman, 1965:4), had become the mother of a disabled child, not the mother of Lea, and her normal identity was spoiled (ibid., 3). Mama Lea herself had become subjected to discreditable stigma related to her unseen attribute of being a mother to a CWD; it was not "only" courtesy stigma that she experienced. Some parents did not only experience marginalization and stigma in their neighborhoods, due to neighbors' treatment of their family they had to move. Finding new housing for a family with a CWD was described as difficult. This resulted in the reality of "shifting from one house to another like a cat with its kitten and it's a great challenge to us" (Mama Ali, 15). Mama Diana's statement shows her experience of stigmatization and the relief she got from her problem oriented coping strategy of moving to another house:

*"The owner of the house where I was living in the beginning was very stubborn so I decided to rent another house with fence. I liked the fenced house because no one will be able to see and laugh at my child" (Mama Diana, 5).*

As seen, moving to another house was described as a coping strategy, at the same time it was a challenge for the parents. However, not all neighbors acted disrespectfully to the parents and their CWD. Parents also talked about neighbors as councilors and supporters asking for the child when he/she was not around. Other neighbors came with well-meant ideas such as "you should make crutches for him", or "don't overfeed him, then you won't be able to carry him".

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<sup>13</sup> Assisting to carry others children is common practice in Tanzanian tradition, seen through observations and expressed during interviews.

These suggestions were painful for parents who found them grounded in neighbors' lack of knowledge concerning their child's disability.

Different strategies existed for coping with challenges related to neighbors and their reactions and treatment of the CWD. Some parents tried to educate them, to increase their understanding, which was a problem oriented strategy. Staying close to their children to defend and protect them was another problem oriented strategy found. One father described that he had to bring his 13-year old son to work to protect him from insulting neighbors. Other parents used more emotion oriented strategies of acceptance and through closing their ears and eyes for the comments they found insulting.

#### 6.2.6 EXTENDED FAMILY AND FRIENDS

Relatives were an important social net with significant influence over the parents' lives. Some relatives were supportive, helpful, and loving which *"has stimulate us in accepting her condition, because in the beginning we were hiding her from others but now we see it very normal"* as described by Uncle Nicole, 13. Other parents described their relatives as more negative and ignorant towards their CWD. As a social net, relatives mainly supported the parents financially, often to cover specific costs like hospital bills. Nevertheless, some relatives were not always happy with continuous begging for money and found it disturbing, parents felt inferior, and in some families these situations caused strained relations. One parent described that their extended family had become distanced to them due to their child's disability. However, in some cases relatives living close to the family gave practical support through baby-sitting or accompanying the parents for health check-ups of the child.

Having a CWD affected parents friendships, since a lot of time had to be dedicated to the child. Some expressed that they lost friends, or told that friends were not as close as before, as *"they know I can't come if they call me"* (Mama Eric, 6). Other friends and workmates tended to give a helping hand to the parents, most often when the child was young. As the child grew up, the support decreased and parents felt lonely and sometimes lost contact with these friends. Davis et al. (2009:67) also saw that parents of CWD had difficulties in maintaining social relationships and a reason was that parents felt they were different than their friends, who had children without disability. The same reasoning could be the case even in this study as parents expressed that friends had become distanced. Relations to relatives changed as it was hard for parents to attend ceremonies like weddings and funerals. For one mother this made here feel isolated and relatives looked down on her, as she did not help out in the preparations and

cleaning up duties related to meetings with her extended family. Grandma Samuel described a baptism ceremony, where she had brought her son:

*“And if you go to gathering where they are baptizing a baby boy... if they are serving sodas, they don't give sodas for him, why?... if I ask can you give me some soda for the baby, well the eyes they look at me, I feel it is unnecessary to ask for it for him... they won't give him a soda because he is lame, he is staying there, the saliva is coming from his mouth... they find him somehow out of society, it is not his place, they find that he does not belong there, but he belongs there, he is a human being“ (Grandma Samuel, 7).*

Grandma Samuel describes her negative experiences of interacting with her relatives, although overall the extended family seems to have a somewhat more understanding attitude towards the parents and their children, compared to neighbors, even though parents on a daily basis interacted more with neighbors than with their extended family. It gives a hint as to the importance of the extended family as a social net for families with CWD. However, the implication of not being able to, or not being allowed to take part in family businesses led to marginalization for the parents and their children, as they were rejected by the norms embedded within the extended family (cf. Ravaud and Stiker, 2001:506-507).

#### *6.2.7 SUPPORT AND REACTIONS FROM OTHER SOURCES*

Parents also described other sources of influence and support on the community level. The church was as a financial contributor that collected money for health care for the CWD or bought things needed for the family. Emotional support in terms of prayer and counselling from the pastor and church members encouraged the parents. Parents found emotional relief and answers to existential questions through this emotion oriented coping strategy, also described in similar studies (Gona et al., 2010; Hartley et al., 2005; Mbwilo et al., 2010; McNally and Mannan, 2013).

All parents interviewed had contact with other parents of CWD, through associations, children's schools or informal networks, as this was how parents were identified for the study. Although, most parents emphasized these relations as beneficial and supportive, since they could talk about their children together and receive inspiration from each other, in a setting where they all were the “normal” parents. Through these contacts the parents got advice on available schools, treatment and aids. The Parents discussed the children's situations, improvements and futures, and exchanged knowledge on how to care for the children. Parents of young children learned what to expect concerning the child's development from those with older children, and how to get prepared for the future. Some parents supported each other practically with physiotherapy and feeding. A strong emotional support existed among the

parents. They encouraged each other and the feeling of loneliness in their exposed situation was reduced when meeting others in similar situations, as described by Mama Victoria:

*“I realize that God didn't create the problems that were meant for me only so we are many parents who have the same problem. This is quite different from previous days were I used to stay alone and think, crying a lot, because I use to see as am alone, so as I have gone to different schools, hospitals and meetings I realized we are so many” (Mama Victoria, 9).*

The relations to other parents of CWD gave the parents what others may receive from the extended family. It is possible that strained relations with relatives therefore were exchanged with stimulating relations with their peer-parents, which clarifies the importance of these relationships.

Reactions and opinions from individuals interacting with the parents on the community level were sometimes perceived by the parents as lack of knowledge regarding disabilities. The parents described ignorance about the child's diagnosis, its source and implications as well as what family life with a CWD looks like. As a problem oriented coping strategy parents tried to inform people they met about their child, but at times became tired of explaining. The foundation was parents longing for equal treatment of their child compared to children without disability and therefore emphasized a need to enlighten people how to interact and communicate with their children. This touches one of the three foundations behind the concept of normalization; all people want to be perceived and treated as human beings (Bronston, 1974:490). The need for the parents to emphasize their child as a human being, with the same rights as other children was obvious when listening to Mama Diana:

*“Some of my neighbors used to insult me by saying: will you stay with your child to the end? Why shouldn't you cry and make noises to people and say that she has died? They meant I have to do something to cause Diana death and say she has died” (Mama Diana, 5).*

A Canadian study, of parenting a CWD, also found problems regarding the community's shortage of knowledge and understanding concerning disability (Hoogsteen and Woodgate, 2013:233), indicating that the problem is present in many part of the world.

### 6.3 RELATIONAL LEVEL

Challenges described at the relational level were connected to the daily life with the CWD, the future, the family situation and the financial situation of the household. Some of the coping strategies were similar to the ones describe on the community level such as striving for education, turning to God and accepting the situation. In addition, problem oriented strategies

described at the relational level included strive for sufficient income, and emotion oriented coping strategies was to accept the situation and to retain hope.

### 6.3.1 THE DAILY CARE FOR THE CHILD

Many parents expressed that they dedicated a large part of the day to care for and supervising the child, a challenge commonly expressed in similar studies from all over the world (Davis et al., 2009; Gona et al., 2010; Hartley et al., 2005; Mbwilo et al., 2010; McNally and Mannan, 2013). The intensified caring included preparation of special food, feeding, support in hygiene and having a great load of washing due to lack of diapers and the child crawling instead of walking. Children able to fend for themselves still needed supervision and encouragement in eating and brushing teeth. To spend a lot of time with the child created strong bonds and parents got to know the child's special needs, expressions and means of communication. Problems of finding people willing to help out in caregiving existed, which generated parents' feelings of being irreplaceable for the child. Even if someone took care of the child for a while, several parents felt like Mama Diana that *"no one is ready to take care of Diana as how I do, so I have to be close to her most of time (Mama Diana, 5)*. Some children with mental problems were stubborn, naughty, and rude, which generated frustration for the parents as well as hardships interacting in the neighborhood and community. Most parents expressed that when the child got sick, the situation became even more challenging and the level of care increased. Many children lacked sufficient means of communication making it hard to locate the sickness, which in turn created anxiety among the parents.

### 6.3.2 FUTURE CONCERNS

When talking about the child's future, the parents consistently returned to the importance of education, as the only way the children would be able to support themselves. For children with more severe disabilities, parents expressed a bleaker future, not knowing what would happen with their child, and there was hopelessness in their voices when talking about their child's future. Some parents, as Baba Adila, said that their children would not be able to have a job or provide for their own living. Some hoped that siblings would take over the responsibility, or that the government would care for their child.

*"And children like Adila, we know them, they cannot do anything, even in the future, they cannot go and work or get employed. What's going to happen to them? We have to think as well" (Baba Adila, 15).*

In a society where children are expected to provide and support parents as they grow old, it is not remarkable that the future becomes uncertain when a CWD is born (Gona et al., 2010). The statement by Mama Faida, describes how others think about her daughter:

*“Others saying that taking her to school is waste of time because she has mental illness hence can’t understand anything. And after school how will she help you with her mental/retarded condition?” (Mama Faida, 8).*

Limited support from society as well as from the government further aggravated parents’ concerns for the future, which was in agreement with similar studies from Tanzania (Mbwilo et al., 2010:10 and McNally and Mannan, 2013:6). The emotion oriented strategy of hoping for God’s healing of the child was, according to the parents, the only way the child’s future situation could be changed. Others asked God to give them good health and a long life to be able to care for the child and see him/her grow up. “God will show me what the future will be like”, was another common statement. Some parents hoped that the disability would disappear and that the child would be able to get a university education and have a job. This could be seen as a survival strategy to retain hope or a strategy of denial, as the same parents also described their child’s inabilities as severe. Problem oriented strategies found were searching for good schools and prioritizing education for their children.

### 6.3.3 FAMILY SITUATION

Most parents interviewed lived together with their spouse and children, and many households also included the older generation of parents, aunts and uncles and sometimes relatives’ children. Older family members gave advice and social support in caring for the CWD, the importance is understood through Mama Andrea, 6: *“I remember it reached a time, if it was not for my mother and father, I could die because I almost drank poison due to life difficulties as I was thinking of my Andrea”*. The main responsibility for the CWD was commonly on the mother, and other family members provided financial means. Families that could afford had a maid who helped in daily care of the CWD. A few children had lost one of their parents’ and in other situations, one of the parents was alive but not present in the child’s life.

*“There [are] two groups of people, some family members seem to care but others don't care and even don't feel concern about him”*. The quote from Baba Mohamed, 16, summarizes the picture of how family members tended to relate to the CWD. A mother described that she was discriminated within her own family; humiliating words about her and her child were spoken, for which reason she had to move far away from them. Several other parents expressed that their CWD was seen as a “normal” member of the family.

It was not uncommon that fathers left the family when realizing that their child had a disability. The first years of the child's life, when the situation of the child was more difficult, seemed to be most critical. Several mothers describe that when the children grew older and developed new skills, the fathers had reconnected with the family and accepted the child. Other fathers punished the mother through offering less money for household expenses and keeping a distance both to their child and to their wife. For the mothers this caused an even more strained situation, which made them dependent on relatives for survival. Acceptance, to stand the situation was an emotion oriented coping strategy. However, to underline, there were also accepting fathers who cared for and loved their child, ready to do everything to support the child and the family. Mama Lea describes a common reality, whereas Baba Adila's exemplifies the exceptional situation:

*"My life has become very, very, difficult even twice as difficult it was in the beginning...as you know mostly if you get a disabled child the husband tends to isolate you. I thank God because he comes to see her and I am living with him, however he is not close as how father could be close to a normal child and even the husband and wife closeness has reduced" (Mama Lea, 6).*

*"It has brought me and my wife and my other children, my family; Adila has brought us more closely. Me and my wife think that there is no way that we can separate" (Baba Adila, 15).*

Similar findings, that fathers tend to leave the family when a CWD was born, have been described in Tanzanian settings previously (McNally and Mannan, 2013:5). A few mothers in this study described that they were blamed for causing the child's disability, and McNally and Mannan saw that as an underlying reason why fathers tended to leave the family. Davis et al. (2010:67) found that Australian parents of CWD also struggled with their marital relationship, and underlined lack of time due to the burden of care as a reason. However, in the Tanzanian context, there are probably other reasons that cause the strained relationships between spouses, possibly related to cultural traditions.

#### **6.3.4 FINANCIAL SITUATION OF THE HOUSEHOLD**

In all interviews, except one, the parents raised financial issues relating to having a CWD. If the financial situation was tough before, it became far more severe after the child was born. In connection to the child's birth, extended hospitalization was often needed, which in several cases undermined the family's financial situation for a long time. The child needed physiotherapy, transportation, school fees, special foods and different aids. One of the parents often needed to stay home, caring for the CWD, with limiting income generating activities for the family as a result. Some parents depended on financial support from relatives and friends, even for their daily needs. Other parents went to relatives in more severe and special cases,

such as when the child was sick. Parents with a relatively stable economic situation, including a full time job, still expressed financial hardships and loss of income connected to the CWD.

Implications of the tough financial situation resulted in fluctuating school attendance for the children, or in other cases no schooling at all. Lack of money for medication, health care, physiotherapy and basic needs such as nutritious food and diapers, were challenging for parents as it negatively affected their child. The financial situation not only affected the CWD, one mother expressed that her other children had dropped out of school as the family's available money had gone to treatment for her CWD. Mama Jana, 6, describes her situation:

*“since she was born my economic situation changed because to care for a child with this type of disability needs you to take much time with her. That means even if you have a job that makes you to earn some money you must stop it. So I decided to take her to her grandparent so that I can work to uplift my economic situation” (Mama Jana, 6).*

Two categories of parents were found, those asking for help from others and those committed to managing the situation by themselves, both seen as problem oriented coping strategies. Some started small businesses that were compatible with having a CWD, like growing vegetables or running a small shop and one parent joined a micro credit organization where they saved a small amount every week. A few parents expressed that all money they earned, they had to save, as they knew expenses related to their child's disability would come.

Receiving a CWD affects the financial situation of the family, as described above and in similar studies (Davis et al., 2009:69; Hartley et al., 2005:167; Mbwilo et al., 2010:10; McNally and Mannan, 2013:5). Baba Adila, presumably a middle income earner, saw that many of his fellow parents of CWD were economically poor and wondered why. He discussed poor education, poor nutrition and lack of knowledge as potential sources that could make economically weak families more prone to receive a CWD. Baba Adila touched on the dual relationship between disability and poverty, described in the first World Report on Disability (WHO and WB, 2011b). To outline the causality between poverty and disability is beyond the scope of this study, although the financial consequences of disability seem to be more severe for affected families in Tanzania, a low income country (WB, 2014), when compared with similar studies done in high income countries (Davis et al., 2010, Emmeron and Hatton, 2007; Sen and Yurtsever, 2007). There are most likely many underlying sources, such as the governmental support, the out-of-pocket system for many services and parents initial economic situation, with limited buffers for unpredictable expense.

#### 6.4 INDIVIDUAL LEVEL

The individual level relates to personal factors and characteristics', describing what is happening inside the individual. Here the focus is on parents' feelings related to being a parent to a CWD. Parents commonly described love, worries, sorrow, pain, loneliness, irritation and hope; discussed in this section. Strategies to cope with negative feelings included acceptance and turning to God.

Most parents interviewed expressed love and affection for their child, the same type of unconditional love most parents experience in relation to their child. In this study, love is seen through the deeper, underlying source of parents' actions, care and efforts for their child. To see the child's improvements and spending quality time together with the child were situations when parents' love, pride and happiness overflowed. Caring for a CWD also produces pressure for the parents, commonly expressed through feelings with negative associations. Worries connected to existential questions like "what will happen to my child when I die?" were expressed by many parents. The continued anxiety related to how relatives would be able to care for the child, which was unable to contribute to the family. The relatives saw the children mostly as burden. Mama Ali, 15, portrays the seriousness in parents' worries: "*we can dare to say that if we parents die our children will be next to die because we are the ones who care for them*". Parents expressed worries of the child not finding employment, which would lead to a life time burden. How the child's health and impairment will develop, and what will happen if the child gets sick, and would there be money to cover treatment and medicines, were other things that worried the parents. Financial worries were often described as many experienced unsustainable financial situations.

Parents expressed an underlying sorrow for the children not being able to live a life like other children, due to the impairment, which corresponds to findings in other studies (Heiman, 2002:160). Mama Lea and Grandma Samuel describe that:

*" it hurts me if I see other normal children of same age as Lea walking comfortable and enjoying life.....but I can't do anything, I can't deny or throw her away.. I accept the situation and she is my child" (Mama Lea, 6).*

*"I want to give him what I can't. I want to give him his feet, I can't. I want to give him the ability to talk, I can't" (Grandma Samuel, 7).*

The sorrow of not being able to give the child what he/she needed and deserved, due to financial constraints was articulated. Some children were able to express their own sorrow of having an impairment, and that sorrow was also transferred to the parents. The pain that the

parents experienced originated mostly from others' opinions and reactions toward the child and the parents themselves. When the child was humiliated, parents themselves felt humiliated and hurt. Loneliness in caring for the child caused feelings of vulnerability. Loneliness was also experienced because of being different and stigmatized due to having a CWD. Parents overtook the stigma and humiliation aimed for their children, in addition they also experienced stigma for being a parent to a CWD, which led to marginalization and discrimination, as discussed earlier. Even if the parents themselves did not have impairment, their experience was similar to that of a person with a disability. Ryan and Runswick-Cole (2008:199) discussed that parents operate as non-disabled people within the lives of their CWD, which gave them a difficult status and limited their opportunities and aspirations. In this study, these consequences were for example parents' limited work opportunities and their worries for the future.

Parents described that children with mental impairments were often described to have a divergent behavior, including rudeness or naughtiness, which made the parents irritated and annoyed, even if they knew the underlying source of this behavior. Worries related to the child's behavior were also expressed; as this behavior could lead to injuries for the child, should they touch fire or not walk carefully on the street.

Even though parents expressed many feelings of negativity, some also showed feelings of hope. There was hope to find good schools that would give the child an education. Hope that the child's impairment would improve in the future and that the child would learn new abilities easing the child's and the parent's situation.

The first emotion oriented coping strategy related to dealing with negative feelings was acceptance, illustrated by Baba Leila:

*"That's why I take it as a normal life style, as did not happen to me alone, there are also others who are caring for children with disabilities, therefore we human beings we get different challenges in different time" (Baba Leila, 4).*

What he describes is the importance of accepting the situation, as nothing could be done to change it. The strategy of acceptance has been described before in relation to others' reaction and opinions about the CWD and their parents, where parents choose not to engage or listen to the comments, as means to endure the situation. For many of the parents, believing in God, the second emotion oriented strategy, was a comfort and their source of hope, which gave relief and help in accepting the situation of having a CWD. Believing that everything happens

according to God's plan and that the child was a gift from God also helped the parents through challenges. Relying on God's care for the future gave parents hope.

## 7. CONCLUSION

This study has explored parents' perception of having a CWD, the findings contained challenges at several different levels. They described practical challenges such as insufficient governmental support, lack of healthcare and education for their child and difficulties in combining professional work and the time-consuming task of caring for the CWD, which generated financial constraints. In relation to people in their surroundings, the parents experienced a mixture of both supporting and helpful persons as well as those meeting the parents with negative attitudes of stigma, discriminating speech and gestures. Parents experienced alienation due to practical challenges connected to their child and due to negative attitudes from others towards to them. This study concludes that the non-impaired parents experienced disablism and disability; similar to that of people with impairments, and that this experience was created due to their child's impairment. Stigma, marginalization and even discrimination were contagious in the context of Dar es Salaam. This says something about the surrounding people's attitudes, knowledge and traditions, which further needs to be studied to generate insight enabling reduction of stigma and discrimination. Likewise, these findings show the importance of including parents in interventions targeting CWD, as well as developing support groups targeting parents specifically.

The parents described coping strategies for dealing with their hardships; some with problem oriented characteristics such as striving for better services for their child and sufficient income for the household, to learn new skills, educate others and staying close to the child. Other strategies were emotion oriented; accept the situation, share experiences with others, retain hope and to turn to God. The discussed coping strategies in this study confirm findings in similar studies, especially those conducted in African contexts. Further, the children's type of disability did not generate any major differences in the parents coping strategies, nor in this study neither when comparing with findings in other studies. Therefore, this study emphasise that parents' coping strategies related to rising a CWD originates in other factors besides the child's type of disability and the context they live in. This indicates ability to share knowledge and experiences across diagnoses and borders, it also leaves room for further research regarding factors impacting the parents coping strategies.

This study used the ecological theory in a new field of application; for structuring parents' individual perceived challenges rather than focusing on the family. In line with existing critique of the ecological theory, issues of separating the theory's different levels arise during the analysis; this is seen in the theme education, which can be connected to three different levels of the theory. Still, the ecological perspective contributed a crystallization of parents' perceptions, which enabled the insight that challenges were rooted in different levels of their surrounding environment. This information is valuable for targeting support interventions, as well as in interventions to reduce stigma and discrimination for parents of CWD. The generated benefit for this study shows the relevance to further tailor the theory to be used in exploring experiences and perceptions in future studies. The analysis of the empirical material saw a clear connection between having a CWD and being exposed to stigma and marginalization. This led to discrimination and parents were seen as a discriminated and marginalized minority group within Dar es Salaam. Simultaneously, the concept of normalization pictured the parents struggle for social inclusion in their community. This knowledge is serious and important, as leaving this large group without special attention may increase inequality with negative implications for the parents and their children, which further could undermine the sustainability of development goals in Tanzania. Recognizing parents of CWD as a minority group, enable action towards full inclusion of PWD and their families in society where they live and interact.

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# APPENDICES

## APPENDIX 1 – INTERVIEW GUIDE FOR FGD

### **Introductory questions:**

1. Tell us about your child.
  - a. Age
  - b. Disability
  - c. Means of communication
  - d. Personality
  - e. Educational situation
  
2. Tell us about your family situation
  - a. Who do you live with?
  - b. Partner
  - c. Children/siblings
  - d. Elderly people in the household

### **Serious questions:**

3. Which challenges do you face in your daily caring for your child?
  - a. Practical
    - i. Physical
    - ii. Time
  - b. Socially
  - c. Communicational
  - d. How do these challenges affect your life?
  
4. How do you react to these challenges?
  - a. Who do you go to for getting help?
    - i. What kind of support do you get?
  - b. What strategies do you use to deal with the challenges you described?
  - c. How well do your strategies mitigate the challenges?
  
5. What do others say about your child?
  - a. How is your child treated within the community?
  - b. How is your child treated in your family?
  - c. How do the surrounding people react to your child?
  - d. How do you feel about these reactions?
  
6. Please talk about the your expectations regarding your child's future
  - a. Which opportunities are you anticipating?
  - b. Which difficulties are you anticipating?
  - c. How do you perceive you child's educational opportunities?

### **Probing questions:**

- Could you talk about that more?
- Help me understand what you mean
- Could you give an example?

## APPENDIX 2 – INTERVIEW GUIDE FOR INDIVIDUAL INTERVIEWS

1. Tell us about your child.
  - a. (Age, disability, means of communication, educational situation)
  - b. Describe your child with 3 words
2. Tell us about your family situation
  - a. (Who do you live with? Partner? Children/siblings (which number is the child with disability?), elderly people in the household)
3. Describe your typical day.
4. How has your life changed since having a disabled child?
5. How does your child's disability affect your family life?
6. Tell me about a positive time with your child. (What is the most positive time with your child?)
7. Tell me about a negative time with your child. (What is the most negative time with your child?)
8. Do you face difficulties/challenges in your daily life with your child?
  - a. Which are those? (Practical (time, practical), social, communicational)
  - b. How do you deal with the challenges you described?
9. How do you react to these challenges?
10. How do these challenges affect your life?
11. Do you get support/help in caring for your child? (From whom? What kind of support? (Time, monetary, other?))
12. What do others say about your child?
  - a. How is your child treated within the, family, neighborhood, community?
  - b. How do you feel about these reactions?
13. What expectations do you have regarding your child's future?
  - a. Which opportunities are you anticipating?
  - b. Which difficulties are you anticipating?
  - c. How do you perceive you child's educational opportunities?

### **Probing questions:**

- Could you talk about that more?
- Help me understand what you mean
- Could you give an example?

