The grace of a fulfilling life

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door
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Belaynesh Tefera

Chapter 1. Introduction

> *I am working in a government office and I am very active in all social areas. We working mothers with disabilities need to use every available resource for the betterment of our families, and our children need to be confident in us. We have to work hard to change the attitudes of society. If we are not competent enough, people may not change their attitude towards us. We need to work hard for a better tomorrow for all people with disabilities. (Interview round two,, 2014, a 39 years old blind single mother (divorced) of three children who has second degree in language and literature)*

When I reflect on my PhD journey, what stands out is the words and facial expressions of the interviewees who inspired, and continue to inspire, me: children with disabilities who are students and women with disabilities who are educated, employed and mothers. The women and children who I became acquainted with during the research project face opportunities and challenges that are profoundly different from the ones that able-bodied people experience, particularly in the context of the developing world. The stigma and discrimination that interviewees struggle with affects their quality of life and ability to achieve valued life goals.

This thesis started with an excerpt from an interview with an amazingly brave woman with a disability. This woman has not let her disability, poverty, stigma, exclusion and discrimination hold her back. She has found a way to transform her challenges into empowerment initiatives to better the life of people with disabilities and their families. Yet, despite her achievements in the workplace, she realises and articulates that, being disabled means to put in much more effort in work than able bodied people to prove her capacity. It also means continuously battling the negative attitudes society has towards people with disabilities.

After I interviewed a number of employed women with disabilities about their experiences in education and work, the women with children sparked my interest as their motherhood is a life changing experience, particularly in relation to being disabled in the Ethiopian society. This experience of motherhood also resonates with me, as I am a mother myself. When I discovered the literature on motherhood, I was overwhelmed by the life experiences of children with disabilities. Thinking about the experiences of women and children with disabilities as a social construct not only appealed to my emerging understanding of disability, it also reinforced my curiosity about disability studies in low and middle income countries (LMICs).

The aim of this thesis is to explore the life experiences of women and children with disabilities in Ethiopia. The focus is on the major social roles played by these women, as students, employees and mothers, as well as the social inclusion experiences of children with disabilities. The data for this thesis were gathered through interviews held on two different occasions (in 2013 and 2014) with 13 women with disabilities and during two focus group discussions held with nine children with disabilities and eight of their primary caretakers in 2017 in Addis Ababa. Studying the life experiences of women and children with disabilities in Ethiopia fills an important knowledge gap. First, there is a need for data in order to understand the (in)equality of opportunities of people with disabilities in LMICs. Second, in LMICs, where disability is often believed to be caused by the wrongdoings of the person's ancestors, explaining what disability really means from the literature and showing the real experiences of people with disabilities who participated in this thesis, may help to improve the attitudes of society towards people with disabilities. This, in turn, can contribute to a better understanding of the needs of people with disabilities and of the fact that these needs must be considered and addressed by society in order for them to be able to participate in roles, such as employee and mother, and reach their full potential.

The research questions addressed in the thesis are:

1. What are the challenges and opportunities that women with disabilities in LMICs face in participating meaningfully in education, employment and family life

2. What factors determine the participation of women with disabilities in LMICs in the important social roles of student, employee and mother, as well as their achievement of valued goals in life?

3. What are the opportunities and difficulties in education and employed life experienced by high achieving Ethiopian women with disabilities?

4. How do opportunities and difficulties in the life experiences of high-achieving Ethiopian women with disabilities affect their achievement of valued goals in life?

5. What are the life experiences of intimacy and marriage, pregnancy, giving birth, and motherhood of women with disabilities in Ethiopia?

6. How do children with disabilities experience social inclusion?

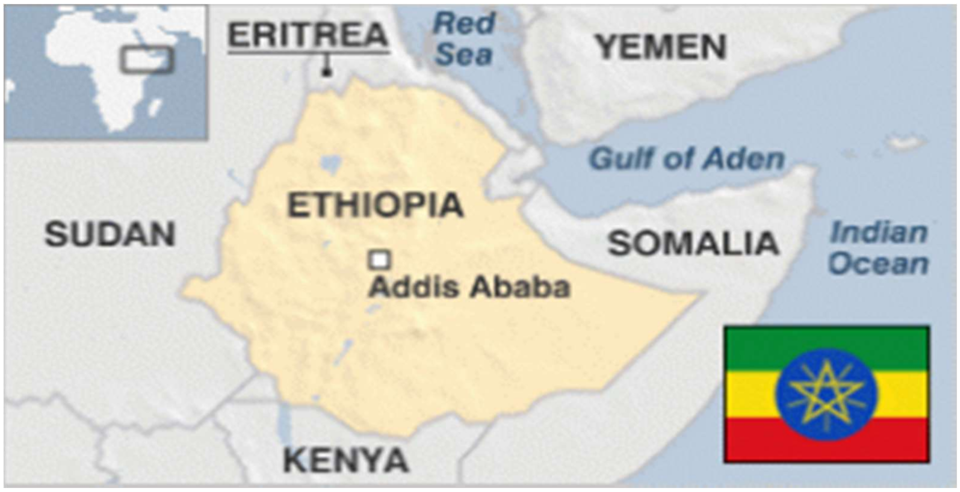
7. What are the primary caregivers' beliefs, attitudes and behaviours in relation to the social inclusion of their children with disabilities?

Understanding the situation of women and children with disabilities in Ethiopia requires a contextual understanding of the country, as well as of disability and gender in the country. Accordingly, the next section (Section 1.1) examines the country context, presents figures on the number of disabled people in the world, in developing countries and in Ethiopia, as well as on the number of women and children with disabilities in Addis Ababa, Ethiopia. In Ethiopia, getting facts and figures on people with disabilities from one source is very difficult, thus the figures for this research are taken from different sources, which were published at different times. As a result, one can find different figures in this thesis from governmental and non-governmental sources. Subsequently, in Section 1.2 the capability approach will be discussed in relation to the life experiences of women and children with disabilities, followed in Section 1.3 by a discussion of the theory of family quality of life in relation to women and children with disabilities. Section 1.4 provides the outline of the whole thesis.

1.1 Background: disability, poverty & gender in Ethiopia

1.1.1 Country context

Ethiopia is located in the Horn of Africa on the continent's northeast coast. It borders six countries: Sudan, South Sudan, Kenya, Djibouti, Somalia and Eritrea. Addis Ababa, the capital, is located in the middle of country and has an altitude range from 100 metres below sea-level on the north-eastern border to more than 4,000 metres above sea-level in the country's mountain ranges(World Bank, 2015a).



Source: World Bank (2015a)

According to the Central Intelligence Agency, over 102 million people live in Ethiopia representing multiple ethnic groups; 19.5% of the population live in urban areas and about 9 million live in Addis Ababa (CIA, 2016), which makes Addis Ababa the fourth most populous capital city in Africa, after Lagos (Nigeria) with 21 million people, Cairo (Egypt) with 20.4 million and Kinshasa (Democratic Republic of the Congo) with 13.3 million people.

Amharic (29.3%) and Oromo (33.8%) are the most commonly spoken languages. Other languages include Somali (6.2%), Tigrigna (5.9%), Sidamo (4%), Wolaytta (2.2%), Gurage (2%), Afar (1.7%), Hadiyya (1.7%), Gamo (1.5%), Gedeo (1.3%), Opuuo (1.2%) and Kafa (1.1%) (CIA, 2016). Approximately two-thirds of the population are Christian (Orthodox 43.5%, Protestant 18.6% and Catholic 0.7%) and a third are Muslim (33.9%). There is also a small proportion who follow traditional religions (2.6%) or other religions (0.7%) (CSA 2007). Traditionally, perceptions of disability in Ethiopian society have stemmed from religious beliefs and social backgrounds.

1.1.2 Attitudes towards disability

In most regions of Ethiopia, families with children with disabilities, especially if born with the disability, are considered to be punished by the village witch doctor or an ancestral spirit. The community, without considering the impact on people with disabilities and their families, often displays humiliating and debilitating attitudes toward people with disabilities. People with disabilities generally share the community's cultural values, beliefs and practices. Children with disabilities often become convinced that the beliefs of society are true resulting in self-stigmatisation (Corrigan, Larson, & Ruesch, 2009). In many instances children and adults with disability become beggars and remain dependant on society for life. In most cases, especially in rural areas, children with disabilities grow up learning from their parents that they are not worthy of mixing with other kids of their age. These children accept this norm and believe that they are being punished by God.

These attitudes are deeply ingrained in Ethiopian culture. For example, Ethiopian musicians typically portray beauty in terms of physical appearance, based on what they view as most desirable. As a result, the beauty and fullness of the body are attributed to the graciousness of God toward that person. If a person is born disabled, it is considered to be due to God's wrath directed at him or her and his or her family. These types of cultural expression portray people with disabilities as less than equal and helpless. Help is mostly provided by family members, especially mothers, who are held responsible for meeting the needs of their children with disabilities.

Because of society's influence, a family with a child with a disability sees the child as a burden. In most cases, families hide children with disabilities for fear of being outcast. They do not consider them to be useful to the community. Some think that people with physical disabilities have intellectual disabilities too, even if the disability is only physical.

1.1.3 Disability and development

Disability is a key development issue. Recent estimates suggest that more than one billion people (or about 15% of the world's population) are living with some form of disability (WHO, 2011). The same source states that lower-income countries have a higher prevalence of disability than high income countries. This source also states that disability is more common among women, older people, and children and adults who are poor.

According to Groce et al. (2013), in Ethiopia, 15 million people are reported to have a disability. There are plans for more in-depth data collection on disability and development through the government and NGOs, such as the Ethiopian Centre on Disability and Development, which should allow for a more precise understanding of the actual numbers involved. In studies by government officials, members of civil society and disability advocates, people with disabilities and their families are reported to face considerable stigma and prejudice (Groce et al., 2013). With 80 distinct ethnic and tribal traditions, there is a range of different attitudes, beliefs and practices towards people with disabilities in Ethiopia. However, in general, people with disabilities are widely believed to be disabled because they or their parents have committed a sin or have angered God in some other manner. Additionally, some disabling conditions, for example epilepsy, are considered to be contagious.

According to the Ministry of Labour and Social Affairs, 95% of people with disabilities in the country live in poverty – the vast majority in rural areas, where basic services are limited and the chances of accessing rehabilitative or support services are remote (Sida, 2014). According to Handicap International, only 3% of Ethiopia's estimated 2.4 to 4.8 million children with disabilities go to school, due to stigma (including by parents and educators), inaccessibility, rigid teaching practices, poorly-trained teachers and lack of adapted learning resources (Sida, 2014). A survey conducted by the African Child Policy Forum in 2011 found that only 29% of children with disabilities were registered at birth. The survey also found that (often preventable) illnesses and complications during birth were the main causes of disability among children (ACPF, 2011).

According to the African Child Policy Forum (ACPF 2011), knowledge about disability is not widespread in Ethiopia: few children with disabilities receive an education; many disabled adults are unemployed; few women with disabilities are married and have children; and outdated traditional beliefs about the cause and nature of disability are common. People with disabilities are often viewed with pity, rather than through an inclusive social or human rights lens. However, a few examples of inclusion do exist. For example, blind people have traditionally worked as singers and musicians. In the Orthodox Church, as well as the Muslim tradition, where religious texts are memorised and recited by scholars, several blind men (Aleka Ayalew Tamiru from the Orthodox Church and Sheik Ahmed Abdulahi Mohammed from the Mosque) have become famous religious scholars. However, these roles are open to only a small number of talented individuals. More widely, those with disabilities are far less likely to be included in the social, economic or political life of their communities, or to receive an education, marry, find work or participate in decision-making at either the household or community level.

In the current social or political structure there is little economic support for individuals with disabilities. In effect, they must either be able to support themselves, live with their family or others who can support them, or turn to begging to support themselves. Although a limited social security system was in place two decades ago, which provided 10–15 Ethiopian birr (ETB) per month (USD 2) for a small number of individuals with disabilities, this system has since crumbled as the country has gone through significant political changes, as well as experiencing a series of natural and humanitarian disasters. A new system of social support is currently under discussion, but is yet to be instituted (Groce et al., 2013).

1.1.4 Poverty and disability

People with disabilities generally experience greater poverty and have lower educational attainment, less access to employment and lower involvement in socially valued roles than people without disabilities (MacLachlan et al., 2017; Mitra, Posarac, & Vick, 2011). The Ethiopian Poverty Assessment 2014 (World Bank, 2015b) states that, since 2000, the pace of poverty reduction in Ethiopia has been impressive, particularly when compared to other African countries. Life expectancy has increased and progress has been made towards the attainment of the Millennium Development Goals (MDG), particularly the goals related to hunger, gender parity in primary education, child mortality, HIV/AIDS, and malaria. While in 2000 only 1 in 5 women in rural areas had an antenatal check-up, in 2011 more than 1 in 3 women attended an antenatal check-up. Women are now having fewer births—the total fertility rate fell from 7.0 children per women in 1995 to 4.6 in 2011—and infant and child mortality rates have dropped considerably, from 35% in 2000 to 21% in 2005 (Susuman, 2012).

As described by the World Bank (2015b), this progress is not without its challenges, however, and poverty remains widespread in Ethiopia. The poorest households have become poorer than they were in 2005; high food prices, which have improved incomes for many poor farmers, have also made buying food more challenging for the poorest. Despite improvements, Ethiopia still has relatively low rates of education enrolment, access to sanitation, and attended births, and challenges remain around investment in the health, safety, and education of women and girls.

Although there is some evidence of manufacturing growth starting to reduce poverty in urban centres at the end of the last decade (2000–2011), structural change, typically from subsistence agriculture to industry and modern services, has been notably absent. The majority of Ethiopian households are still engaged in agriculture and living in rural areas. Additional drivers of poverty reduction are needed to end poverty in Ethiopia, particularly those that encourage the structural transformation of Ethiopia's economy (World Bank, 2015b).

1.1.5 Human development index

According to the World Bank (2016), Ethiopia is the second-most populous country in Sub-Saharan Africa, with a population growth rate of 2.5%. National and international reports

(World Bank, 2016; Organisation for Economic Co-Operation and Development: Development Centre, 2016) indicate that the Ethiopian economy has experienced double digit growth, with an average growth rate of more than 10%, which is double that for Sub-Saharan Africa as a whole. Expansion of the services and agricultural sectors (46.6% and 38.8%, respectively) in 2015 accounts for most of this growth, while the manufacturing sector contributed only 4% of GDP in 2015 (Organisation for Economic Co-Operation and Development: Development Centre, 2016).

Although, the contribution of the service sector has been improving (it increased from 40% in 2005 to 46% of GDP in 2015), agriculture remains the core sector in terms of its contribution to the overall economy: it is still a major source of food for domestic consumption, a primary source of commodities for export, and of raw materials for domestic manufacturing industries. Moreover, the service sector contributed 77% of total employment in 2015 (Organisation for Economic Co-Operation and Development: Development Centre, 2016)

According to (UNDP (2015), Ethiopia partly achieved the MDGs, particularly the goals relating to reducing child mortality and improving water coverage. There has also been encouraging progresses in terms of gender parity in primary education and reducing HIV/AIDS and malaria. In addition, Ethiopia has a good track record in achieving universal primary education coverage during the last 15 years (World Bank, 2016).

Despite all these positive changes and achievements, poverty and underdevelopment are still serious problems in Ethiopia. According to the World Bank (2015a), GDP per capita in terms of purchasing power parity (PPP) in Ethiopia was USD 1,530 in 2015, which is 10.5% of the world's average GDP per capita. In the same period, the total national income for all nations of the world was valued at more than USD 74 trillion, of which over USD 48 trillion originated in the economically high income countries. According to World Bank (2015a), this is 200 times more than what was generated in the less developed nations, even though developing countries represent five-sixths of the world’s population.

As UNDP (2015) reports, the world average human development index (HDI) value in 2014 was 0.771, while Ethiopia’s HDI value for the same year was 0.442, which put the country in the low human development category, with a position of 175 out of 188 countries and territories. The report further indicates that Ethiopia’s HDI value increased between 2000 and 2014, from 0.284 to 0.442, which is an increase of 55.6%. However, Ethiopia’s position is still below the average for other Sub-Saharan countries (which was 0.518 in 2014) and below Sub-

Saharan countries that are similar to Ethiopia in terms of HDI rank and population size (such as Rwanda and Uganda, which both have a HDI ranking of 163).

The same report states that life expectancy at birth in Ethiopia was 64.1 in 2014, which was 23.5% higher than in 2000 and 20.4 years more than in 1980. In this respect, life expectancy in Ethiopia has shown improvements and is a little higher than the average for Sub-Saharan African countries, which is about 58.5 years. However, it is still lower than the world average life expectancy, which was 71.5 years in 2014.

1.1.6 Women and children with disabilities

The normative belief in Ethiopian society is that girls should stay home with their mothers, help with the household chores and learn to cook for their future family. This is reflected in a local proverb that says: *"Women and pot should be kept in the kitchen".* This belief limits Ethiopian women from taking on major social roles in education and employment.

There have been few studies concerning women in Ethiopia, but many observers have commented on the physical hardships that they experience throughout their lives. A local proverb says that: "*A woman and a donkey can bear a rainfall".* The hardships borne by women include carrying loads over long distances, grinding corn manually, working in the homestead, raising children and cooking. Ethiopian women have traditionally suffered sociocultural and economic discrimination and have fewer opportunities than men for personal growth, education and employment. Even for empowered women, there are sayings like: *"Where a woman rules, streams run uphill",* implying that women create unnecessary hardships when they hold leadership positions and direct others. Women in Ethiopia are also expected to get married and have children. An unmarried woman is assumed to lead a low quality life, as the following saying implies: *"A woman without man is like a field without seed".* If the children of an unmarried or divorced mother make mistakes or behave badly, people attribute their behaviour to the fact they were raised by a single mother and say that: *"A child raised by a woman looks like [....leaving a silence]*. It is believed that mothers cannot teach ethical behaviour to their children, but instead pamper their children. Ethical behaviour is believed to be learnt from the father (Bahiru & Mengistu, 2018).

The social expectations on children and women with disabilities regarding socially-valued roles, such as those in education, employment, and married life, as well as their social inclusion, vary from those of people without disabilities. The next sections examine their participation in these roles, applying the theories of the capability approach and family quality of life.

1.2 Capability approach

The capability approach (CA), developed by Nobel prize laureate Sen, is an ethical framework that states that social justice should focus on supporting the capabilities of all individuals to conceive, pursue, and achieve their life plans (Sen, 1999; Venkatapuram, 2011).

The CA focuses on the type of life that people are able and enabled to live—that is, on peoples' capability to succeed in being or doing what they value in life. In the capability approach, the possession of means or commodities is valuable only to the extent that it enables the person to do or be a variety of things, through using and 'converting' such means into outcomes. For Sen, equity in opportunities or capabilities (i.e., the 'freedom to achieve' the important goals that people have) is important, not equality in means or commodities. Moreover, a commodity has different meanings for different people in different situations. For instance, for a blind person, Braille technology has the meaning of enabling them to read or write; it does not have such meaning for a person who has sight (Mitra, 2006).

In Sen's approach, capability is understood as the "practical opportunity" to fulfil 'functionings' or "beings and doings [that] people have reason to value" (Sen, 1992). The ordinary meaning of functioning is an activity—something that a person does. In the CA, functioning has a broader meaning; it includes activities as well as desirable states, such as "being well nourished" or "being free of malaria". Sen illustrates the difference between capabilities and functioning through the example of two people who are starving. One is starving due to religious faith (she has decided to starve, as a free choice), whereas the other is starving because of poverty, with no choice (Sen, 1983, 1993). They achieve the same functioning, i.e., undernourishment, but have different sets of capabilities.

The capability approach looks at what is valuable to, and valued by people and how they can achieve a valuable life. The approach states explicitly that it is the shared responsibility of the individual and the social context to build up and facilitate a person's capability set so that they can be enabled to achieve a valuable life. Sen is concerned with a person's interests, more than a person's actions or behaviours. Sen differentiates between a person's "wellbeing" and "advantage". Wellbeing concerns how "well" a person is functioning in terms of actually being or doing. In Sen's view 'satisfaction' or 'happiness' are not sufficient or valid indicators of wellbeing, because people adapt to their circumstances. A beggar can be very happy if someone gives him or her fifty euro while a billionaire may be unhappy if a hedge deal yields 'only' ten million euro. Advantage refers to the real opportunities from which the person has the freedom to choose.

With respect to achieving a given capability, costs differ according to the situation and environment, including the level of wealth of the society a person lives in. This also applies to persons with a disability. The local accessibility of assistive technologies strongly determines the cost of acquiring mobility and is one of the causes of variations between countries (Mitra 2006).

The applicability of the capability approach is fostered by its flexible, open features. It does not express personal traits, abilities, environmental aspects and functionings in a single metric. According to Mitra, 2006, rather than suggesting one definite measure of wellbeing, Sen advocates for interpreting variables in their context. For instance, education can be interpreted as a ‘personal characteristic’ that influences work performance, as a ‘functioning’, enabling a level of work that the disabled person can do as a consequence of his/her level of education or as a ‘capability’, depending on the opportunity one has to acquire education. In line with this, the approach covers a wide range of functionings (from those reflecting basic needs to more complex ones, such as ‘self-actualisation’). From a disability perspective, this range would begin with accessing the basic needs of mobility and participation, culminate in actualising ‘self-respect’, confidence and public appearance (Alkire, 2002). An important feature of the CA is that it is a normative approach for propagating equity, In the CA, disabled people have an entitlement or claim to more assistance because of the impediments they have in converting their resources into capabilities and valuable functionings.

1.3 Family quality of life

Children and women with disabilities in low and middle income countries such as Ethiopia face the simultaneously presence of disability, poverty and, for women with disabilities, gender. The intersection of these social disadvantages creates stigma-related discrimination in various life domains, which impacts on the quality of life for children and women with disabilities, and their families.

Theoretically, quality of life (QoL) concepts vary, but there are overarching and commonly accepted ideas, including life domains that have meaning to people and can be perceived differently by persons with disabilities and their families (Brown & Faragher, 2014). QoL is composed of domains such as emotional wellbeing, physical and material wellbeing, family and social interactions, and disability-related support (Schalock et al., 2002; Brown, Schalock, & Brown, 2009). These life domains are conceptualised in (family) QoL constructs that reflect a sensitising approach and provide a framework for understanding disability (Brown & Faragher, 2014). QoL can be seen as a model that recognises what is important, necessary and satisfying in someone's way of life. It can be understood as the achievement of goals in major life settings at a personal level and the social wellbeing of families and important others (Schippers & van Heumen, 2014).

Worldwide, families are considered to be a universal basic structure in society (Samuel et al., 2012) and can be defined as: "two or more people who regard themselves as a family and who carry out the functions that families typically perform; these people may or may not be related by blood or marriage" (Poston et al., 2003, p. 319). Family, in the Ethiopian context, refers to people who live in households together, which includes not only the nuclear family (mother, father and children), but also members of their extended family (grandparents, aunts, uncles, cousins and others). Family members act as both an economic and emotional network and provide individuals with a sense of who they are and where they belong.

Family quality of life (FQoL) emerged from individual QoL concepts, focusing on the family as a unit, where individual family members experience their QoL and where the quality of family life as a whole is experienced (Samuel, Rillotta, & Brown, 2012; Zuna, Brown, & Brown, 2014). In the application of the concept of FQoL in practice, the family is recognised as an important resource for persons with disabilities, while at the same time disability impacts on family life (Samuel et al., 2012 Brown et al., 2009). In the FQoL concept, the positive contribution of living with disability to families and communities is also recognised, whereas other disability related family concepts focus only on the negative impact of disability on family life, such as coping and stress (Zuna et al., 2014). Faragher and Van Ommen (2017) conclude that: "FQOL helps to understand the factors involved to explain why some families flourish in the presence of disability while others do not" *(ibid*., p. 42).

1.4 Thesis outline

The thesis is made up of a number of articles on the education, employment and motherhood equality challenges and opportunities of women with disabilities in LMICs. The findings are interpreted using the theories of capability approach and social role valorisation. It also explores the opportunities that women with disabilities have acquire despite the problems they face due to the intersectionality of gender, disability and poverty, starting at school and continuing into their employment. This is stated as the disability paradox (Albrecht & Devlieger, 1999). Subsequently, the thesis explores the life experiences of women with disabilities in relation to intimacy and marriage, pregnancy, birth, and motherhood. The thesis also explores the social life experiences of children with disabilities in relation to the themes of ‘being’ (which is about who one is), ‘belonging’ (which involves feeling included by valued others in the environment), and ‘becoming’ (which refers to the purposeful ‘doings’ to achieve personal goals, hopes and aspirations)(Zekovic & Renwick, 2003), to explain the social inclusion and/or exclusion of children with disabilities using the theories of capability approach and family quality of life . Table 1.1 summarises the different research questions, the research design used to answer the questions, and the chapters in which each research question is dealt with.

Table 1.1 Research questions and design

Research question	Chapter	Research design
1. What are the challenges and opportunities that women with disabilities in LMICs face in participating meaningfully in education, employment and family life? 2. What factors determine the participation of women with disabilities in LMICs in the important social roles of student, employee and mother, as well as their achievement of valued goals in life?	2	A systematic literature review of articles selected from Web of Science, PsychINFO, Google Scholar, and MEDLINE on education, employment and family life in LIMCs published between 2006–2015
3. What are the opportunities and difficulties in education and employed life experienced by high achieving Ethiopian women with disabilities? 4. How do opportunities and difficulties in the life experiences of high-achieving Ethiopian women with disabilities affect their achievement of valued goals in life?	3	A qualitative study using a modified grounded theory approach to analyse in-depth, semi-structured interviews with 13 educated employed women with disabilities from the Addis Ababa metropolitan area
5. What are the life experiences of intimacy and marriage, pregnancy, giving birth, and motherhood of women with disabilities in Ethiopia?	4	A qualitative study using an inductive coding approach to analyse in-depth semi-structured interviews with 13 employed mothers (8 follow-up interviews with women that were interviewed for chapter 3 and 5 new interviews) with disabilities from the Addis Ababa metropolitan area
6. How do children with disabilities experience social inclusion? 7. What are the primary caregivers' beliefs, attitudes and behaviours in relation to the social inclusion of their children with disabilities?	5	A qualitative study: The simultaneously inductive and deductive thematic analysis of (i) a focus group discussion with 9 children with disabilities and (ii) a focus group discussion with 8 primary caregivers of children with disabilities.

In Chapter 2, the challenges and opportunities faced by women with disabilities in LMICs, resulting from disability, gender and poverty, are examined. A literature review identified 24 published articles on women with disabilities in education, employment and motherhood, which were analysed for this chapter. Grounded theory was used as a method for rigorously reviewing the literature. The review describes the difficulties women with disabilities in LMICs experience in participating and succeeding in education, employment and motherhood and how access to education, employment, intimacy and marriage is hampered by (i) stigma and cultural practices resulting in discrimination and prejudice, and (ii) lack of support from family, teachers and institutions. Support from families, communities, the government, and non-governmental organisations and reducing poverty are highlighted as important for improving women's ability to fulfil their social roles (as students, employees and mothers).

In Chapter 3, the study shows how difficult life experiences, such as those resulting from disability, can be challenging in a developing country such as Ethiopia, but can also contribute to the resilience of disabled women in their working life. The analysis was based on interviews with 13 educated women with various physical disabilities. The chapter highlights a number of paradoxes. For example, a person's disability can on the one hand hamper his/her opportunities to reach a valued goal in life, while on the other hand providing opportunities that would not have been there without the disability. The study sheds light on the belief that disability is the result of wrongdoing by the family of the person with a disability. These beliefs and traditions have unintended consequences for disabled women such as dislocation from their places of birth and separation from family. The paradoxes that are exhibited in this chapter are (i) the paradox of disability and educational opportunity, (ii) the paradox of separation from family and success, (iii) the paradox of hardship in obtaining employment and related opportunities and strength, (iv) the paradox of disability hardships and self-confidence and self-reliance, (v) the paradox of disability and improved quality of life, and (vi) the paradox of support and dependency.

In Chapter 4 the motherhood experiences of women with disabilities in Addis Ababa are explored. Interview data with 13 mothers with disabilities (eight follow-up interviews with interviewees from the study presented in Chapter 3 and five new interviews) revealed that, in addition to certain rewards that these mothers associate with their experiences as mothers, they face significant challenges in relation to the accessibility of health care centres, lack of knowledge among physicians about disability and problematic attitudes toward people with disabilities, and, more generally, social prejudices towards people with disabilities. The study highlights that the interviewees find agency, achievement of valued goals in life, and pride in their experiences of intimacy, pregnancy, and motherhood. This enables them to face physical and material challenges, negative societal expectations, and hardships.

Chapter 5 presents the findings on the social inclusion experiences of children with disabilities, based on two focus group discussions with children with disabilities and the primary caretakers of children with disabilities. The results indicate that children with disabilities, as well as their siblings and other family members often experience social exclusion. On the other hand most children report a high social inclusion within their families and among children with similar disabilities they interact with in educational institutes. Furthermore, both children and their primary caretakers emphasize that 'to be socially included' is a capability as such, as well as a means to achieve (other) valued capabilities or 'functionings', including leisure activities, communication, social activities, education, mobility.

Finally, in Chapter 6, the key findings of the four chapters are presented and discussed, followed by theoretical and methodological reflections. This is followed by a discussion of the contributions and implications of the research. Subsequently, suggestions are made for future research on the lives of women and children with disabilities in low and middle income countries. Subsequently, the conclusion of the whole thesis is presented

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Chapter two

Education, Work, and Motherhood in Low and Middle Income Countries: A Review of Equality Challenges and Opportunities for Women with Disabilities

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Abstract

This study looks at the equality challenges and opportunities for women with disabilities in low and middle income countries (LMICs) to participate and succeed in education, employment and motherhood. It is based on a systematic review of the literature from academic and non-governmental organization databases. The search of these databases yielded 24 articles, which were subsequently passed through open, axial, and selective coding. The resulting review found that women with disabilities in LMICs have severe difficulty participating and succeeding in education, employment and motherhood due to a number of interrelated factors: (i) hampered access to education, employment, intimacy and marriage, (ii) stigma and cultural practices resulting in discrimination and prejudice, and (iii) lack of support from family, teachers and institutions—all of which are exacerbated by poverty. Support from families, communities, the government, and non-governmental organizations improves women's ability to fulfil their social roles (as students, employees and mothers), resulting in a better quality of life. Strategies that create awareness, minimize poverty and facilitate justice may improve the opportunities for women with disabilities in LMICs to participate in education, employment and motherhood, as well as their ability to succeed in these domains.

Keywords: capability; disability; education; employment; low and middle income countries; motherhood; social roles; women with disabilities

1. Introduction

Participation in social roles that are valued by society can lead to many benefits for those who have the opportunity to take on these roles (Osburn, 2006). Among other things, these benefits may include: a sense of belonging, an education, the development and exercise of one's capabilities, opportunities to participate in society, a decent material standard of living, and opportunities for work and self-support (Osburn, 2006; Wolfensberger, Thomas, & Caruso, 1996). The purpose of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities (Article 1), and it sets out a number of rights of persons with disabilities, including the right to education and employment on an equal basis to others, as well as certain rights related to family and reproduction (United Nations, 2006). The Convention recognises that "disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others" (Preamble, para. e, United Nations, 2006). It requires states parties to be aware that persons with disabilities enjoy legal capacity on an equal basis with others and should be supported to exercise their legal capacity (Article 12, United Nations, 2006). The Convention makes the participation of persons with disabilities one of its principles and enshrines the right of disabled persons to participate fully and equally in the community, in education, and in all aspects of life. According to the World Disability Report (WHO & World Bank, 2011), participation in social roles by people with disabilities is much more limited than participation by the general population; this is particularly true for women with disabilities, who suffer double discrimination on account of disability and gender. The 2030 Sustainable Development Agenda (6), which is captured in the Sustainable Development Goals (SDGs) (7), states that addressing the needs of, and barriers faced by, people in disadvantaged groups is a prerequisite for an inclusive and equitable society. This is reflected in the pledge 'leave no one behind'.

Understanding the opportunities and challenges that women with disabilities in low and middle income countries (LMICs) face in participating meaningfully in education, employment and family life (Tefera & Van Engen, 2016; Tefera, Van Engen, Van der Klink, & Schippers, 2017) is critical, not only to the articulation of inclusive development theories, but also to the design of appropriate (family) interventions to improve quality of life. While there has been increased interest in disability issues in developing countries, there is limited data available in this field

(Loeb & Eide, 2008). The existing data is often fragmented and anecdotal (Groce, Kett, Lang, & Trani, 2011). The small, but growing, literature base indicates that the substantial links between education, employment and family life are more multifaceted and interrelated than previously assumed. The intersectionality of high levels of poverty with gender and disability in LMICs makes disability equality substantially different in these countries than in high income countries, which are also typically better researched. Our review, therefore, focused specifically on disability equality in LMICs.

To critically analyse all present and published knowledge, we systematically reviewed the literature on LMICs that looks at the relationship between education, employment and motherhood as providing access to the major social roles of student, employee and mother in order to answer the following research question:

> What are the important challenges and opportunities for women with disabilities in low and middle income countries to participate in education, employment and motherhood, and what factors determine their participation in the important social roles emerging from these (of student, employee and mother), as well as their achievement of valuable goals in life?

In the following paragraphs we introduce the concept of ‘social role valorization’ (SRV); Osburn, 2006; Wolfensberger, 1983; Wolfensberger & Thomas, 2005) and the capability approach (Nussbaum, 2006; Robeyns, 2005; Sen, 1983, 2009), which will be used as a guiding framework to understand disability inequality in participation in social roles and the achievement of valuable goals in life. Subsequently, we present the literature review, with a focus on the roles that women with disabilities have as students, employees and mothers. In the discussion of this review, we will argue that these roles are interrelated, as achievements in one impact on opportunities in the others.

2. Theoretical Framework

The social roles that individuals identify with and that others in society attribute to them vary. The concept of shaping social roles by means of enhancement of competencies and image is referred to as SRV, a term coined by Wolfensberger (1983). Women with disabilities can identify as students, employees, mothers and so forth. These roles are valued in society—but not all people are valued by society. People with disabilities are often societally devalued, or at high risk of becoming devalued (Osburn, 2006). For example, society does not identify women with disabilities as capable of playing a valuable role as students, employees or mothers. Adopting valued social roles allows women with disabilities to engage in meaningful activities, which promotes self-esteem and confidence, which, in turn, helps them to improve their quality of life (Osburn, 2006; Flynn & Aubury, 1999; Gardner & Carran, 2005; Lemay, 2006). Ultimately, participation in valued social roles can lead to the adoption of other valued social roles. For example, a woman with a disability who is educated and employed may be confident enough to strive for additional socially-valued roles, such as marriage and motherhood.

As stigma is imposed on women with disabilities, and cannot be ‘disposed’ of, women often tend to internalize and accept society’s negative evaluation. Being stigmatized results in rejection, exclusion and discrimination, thus limiting the opportunities for women with disabilities to achieve their potential and increasing the likelihood of poor treatment by others in society. Wolfensberger and Thomas (1994) emphasize that if people are devalued by society, or are at risk of being devalued, their acquisition of valued social roles may decrease the stigma and discrimination they experience.

Another framework that can help us to understand the disability inequality of women in LMICs is the capability approach. This approach, introduced by Sen (1980, 1993, 2009), is a normative approach that states that individuals should have the capabilities to conceive, pursue, and revise their life plans (Alkire, 2002, 2005; Nussbaum, 2006; Robeyns, 2005; Sen, 1999; Venkatapuram, 2011). Society or societal institutions should enable people to achieve these capabilities. There are three important elements in the capability approach, namely: *capabilities*, *functionings* and *freedom*. In the most basic sense, functionings represent the states and activities that constitute a person’s being: “beings and doings people have reason to value” (Sen, 1992, p. 40). The capabilities of an individual reflect the different combinations of functionings that a person is able to achieve, depending on his or her particular circumstances—in other words, the various combinations of what s/he can do or be. According to Sen, an individual’s well-being should be assessed in terms of capabilities (potentials to achieve), as functionings (achievements) may be the result of constrained choices or reflect a limitation in choices.

So, it is important to evaluate what an individual can do, or is able (and enabled) to do, and not just what they actually do. Capabilities represent a person's opportunity and ability to achieve valuable outcomes, taking into account relevant personal characteristics and external factors: being able and enabled.

In the capability approach it is recognized that all people are different in terms of their resources and characteristics. Because people differ in terms of these 'inputs', people also need different means or 'conversion factors' to achieve equity in opportunities and outcomes. Therefore, in the capability approach, justice is not considered to be *equality in means* (everybody has the right to the same means), but *equality in outcomes* (everybody should have the same opportunity to achieve valuable outcomes). Hence, equality for women with disabilities is about having the opportunity and ability to shape one's life in terms of one's valued goals in relation to education, employment and motherhood, which might require extra means for this group. This emphasis on equality in outcomes is in accordance with the above mentioned requirement of the CRPD (Article 12, United Nations, 2006).

3. Method

The review methodology by Hannula, Kaunoen and Tarkka (2007, p. 105) was followed for the literature review. By exploring and evaluating findings of previous published research, a review constitutes an essential aspect of all research related to the themes, enabling the work to be set in the context of what is known and what is not known (Saunders & Rojon, 2011). Grounded theory, as a method of rigorously reviewing literature, was used during the analysis stage (Wolfswinkel, Furtmueller, & Wilderom, 2013). This method involves five steps: define, search, select, analyse, and present. Several databases were used to identify suitable articles: Web of Science, PsychINFO, Google Scholar, and MEDLINE. The keywords and combination of keywords used to search all databases included: "(disabled women or women with disabilities) OR (low or middle income countries or Global South), OR education OR employment OR (motherhood or intimacy or marriage) OR family life". The criteria for the inclusion of articles were: (i) published in English, (ii) full article accessible, and (iii) peer reviewed and published during the period 2006–2015. Articles were excluded when: (i) there was no reference to women with disabilities, (ii) developing or low or middle income countries were not addressed, and (iii) there was no reference to either of the three themes (education, employment, or motherhood) and no reference to the terms disabled, disabling, disability or disabilities. A total of 25,566 articles were initially identified and included in the search.

The selection process is outlined indicated in Chart 1, which shows the coding process from the database selection up to the final coding round and the final selection of articles to analyse.

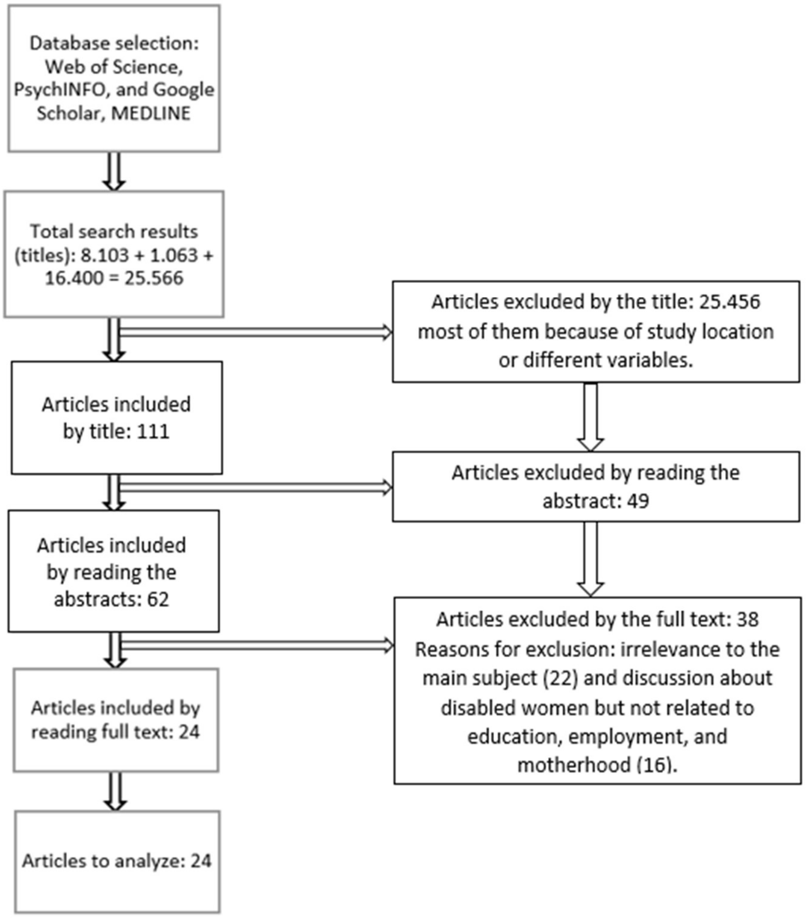

Chart 1. Study selection process.

4. Coding

The analysis stage passed through open, axial and selective coding. In the open coding, all statements about education, employment and motherhood were selected. During the axial coding, concepts were categorized based on the three themes (education, employment, motherhood). Repeated ideas (different authors using similar terms to explain the same idea of discrimination in relation to the themes) were included if they were expressed in different ways. Two coders (first and fourth author) independently selected key fragments from the articles on the themes of education, employment and motherhood, producing a table that also included some of the study characteristics of the articles (e.g., sample information, methodology). The two tables were compared by the second and third author and a final table created, which was subsequently used for the analyses (available from the authors upon request).

5. Description of Sample

The 24 articles follow different methodologies. There were: 11 qualitative studies (Braathen & Kvam, 2008; Dhungana, 2007; Kassah, Kassah, & Agbota, 2013; Kiani, 2009; Kvam & Braathen, 2008; Lamichhane, 2012a; Mitra, Posarac, & Vick, 2011; Morrison et al., 2014; Naami, Hayashi, & Liese, 2012; Simkhada et al., 2013; Tuomi, Lehtomäki, & Matonya, 2015), 7 reviews (Emmett & Alant, 2006; Groce et al., 2011; Moodley & Graham, 2015; Opini, 2010; Ortoleva, 2010; Parnes et al., 2009), 1 quantitative study (Naami, 2015), 2 mixed studies (qualitative and quantitative) (Lamichhane, 2012b; Salome, Mbugua, & Ong'eta, 2013), 1 examination of UN disability convention proceedings (UN & UNC, 2012), 1 examination of domestic legislation (R. Gupta, 2013), and 1 conference paper (which is on the right to autonomy and self-determination) (Frohmader & Ortoleva, 2013).

6. Results

This section presents the results of the literature review in terms of how access to education, employment, intimacy and marriage; stigma related to cultural values and cultural practices; and support (or the lack thereof) influences the participation of disabled women in education, employment, and motherhood and family life.

6.1. Education

In the literature reviewed, there are 16 articles that mention the education issues of women with disabilities in LMICs. In a study using the World Health Survey data, Mitra et al. (2011) compared 15 developing countries in Sub-Saharan Africa, Asia and Latin America in terms of the prevalence of disability and differences between individuals with and without disabilities for several indicators of poverty, including the proportion of primary school completion. In all countries, except Burkina Faso (where lack of primary school education is low in general, less than 89%), the proportion of primary school completion rates is lower among persons with disabilities. In Mauritius and Zimbabwe, primary school completion for persons with disabilities is about the same as for persons without disabilities. In other countries, such as Ghana, Kenya, Malawi, Zambia, Bangladesh, Lao PDR, Pakistan, Philippines, Brazil, Dominican Republic, Mexico and Paraguay, the difference in primary school completion rates between persons with and without disabilities is somewhat smaller. Mitra et al. (2011) conclude that, in terms of poverty (using a multidimensional indicator of poverty including education), women generally fare worse than men. Unfortunately, there are no analyses comparing poverty among men and women with and without disabilities.

In a study using different sources of panel data, Moodley and Graham (2015) compared the education level of men and women with and without disabilities in South Africa. They found that the higher you go in terms of education level, the lower the completion rate of women and men with disabilities. Although primary school completion among men and women with disabilities is higher (26.1% and 28.6%, respectively) than among men and women without disabilities (21.4% and 20.0%, respectively), the reverse pattern is found with higher levels of education: 32.7% of men and 30.8% of women with disabilities have ‘some secondary education’, compared to 50.6% of men and 48.4% of women without disabilities. The proportion of individuals with completed secondary level education is smallest for women with disabilities (9.2%), compared to disabled men (12.8%), non-disabled women (16.6%), and non-disabled men (16.5%). Tertiary education attainment is low: 1.6% for non-disabled men and women, compared to 0.7% for men and women with disabilities. In a large survey among men and women with disabilities (in which 42.1% of the respondents were women with disabilities) conducted in the Kathmandu valley of Nepal, Lamichhane (2012a, 2012b) found the average years of schooling for persons with disabilities to be 8.8 years, compared to the country average of 9.4 years. However, those with hearing impairments (6.9 years) had much less schooling than those with visual (9 years) or physical impairments (10.9 years).

6.1.1. Accessibility

Reports that review different databases (Mitra et al., 2011; Opini, 2010; Parnes et al., 2009; UN General Assembly, 2012) conclude that women with disabilities face more difficulties than men with disabilities, or people without disabilities, in gaining access to education. For many of those who do access education, the continuation of education is also an issue. A study by Kassah et al. (2013), which interviewed five women with physical disabilities in Ghana who had faced physical abuse, found that the women did not complete school because of inability to pay school fees. Braathen & Kvam (2008) also found lack of money to be a main reason for quitting school early, while Kiani (2009), in explaining the perceived inability of women with disabilities in Cameroon, noted that some families prioritize their non-disabled daughters when paying school fees, as they believe educating women with disabilities is a waste of money.

Other reasons for discontinuing education mentioned in the articles were: physical inaccessibility of schools (Braathen & Kvam, 2008; Kiani, 2009), inadequate training of school teachers (Padam P Simkhada et al., 2013), and lack of encouragement from teachers (Tuomi et al., 2015).

6.1.2. Stigma Related to Cultural Values and Practices

A number of articles cite societal expectations that women with disabilities are either unable or unworthy of education as a major reason for lack of education opportunities. Kvam & Braathen in their study of the daily lives of 23 women with disabilities in Malawi (2008a) and follow-up study by Braathen & Kvam, using focus groups and interviews (2008b), as well as Lamichhane (2012a), who studied the employment situation of 402 persons with disabilities in Nepal, describe how the societal expectation that women with disabilities do not need education or special schools hinders women with disabilities from participating in education. Simkhada et al. (2013), in their qualitative exploratory study of knowledge and attitudes towards women with disabilities in rural Nepal, found that women with disabilities in LIMCs suffer from limited availability of resources for education (e.g., Braille facilities), because resources are channelled to non-disabled students, as women with disabilities are considered incapable of participating in education. Salome et al. (2013) report that low expectations by teachers and peers undermine female students' self-esteem. Female students are also teased and taunted by their peers and teachers and reported told that they are incapable of achieving high grades. Moreover, they also report that many women with disabilities experience gender based violence while undergoing education (Salome et al., 2013).

6.1.3. Support and Lack of Support

Four of the articles reviewed indicate family resistance to the education of women with disabilities (Dhungana, 2007; Bente Lilljan Lind Kassah, Alexander Kwesi Kassah, & Tete Kobla Agbota, 2013; Kiani, 2009; Lamichhane, 2012a). Some families not only deny girls with disabilities access to school, but hide them away due to fear of stigma (R. Gupta, 2013; Lamichhane, 2012b). Kassah et al. (2013) explain the lack of support from parents and other family members as reluctance to support their daughters with disabilities. Respondents in that study indicated that families prioritize the education needs of their non-disabled children, because they believe that educating children with disabilities is a waste of resources.

Yet, paradoxically, some articles mention that educating women with disabilities promotes their acceptance by their family and society. For example, Tuomi et al. (2015) note that educated women with disabilities gain value and respect within their family and are allowed to take part in family discussions and decision-making. Braathen and Kvam (2008a) found that educating women with disabilities makes them more confident.

Several articles also stress the importance of support within the education system. Emmett and Alant (2006), for instance, conclude this from a pilot study that interviewed Tanzanian women with disabilities in higher education. Tuomi et al. (2015) found clear indications that services, such as guidance and counselling, contribute to the success of women with disabilities who have started education. The authors acknowledge that the extra help received by disabled women contributes significantly to their success; for example, some teachers give women with disabilities preferential seating, which enables these students to become known to their teachers.

6.2. Employment

There are 14 articles that discuss the participation of women with disabilities in LMICs in employment. In some articles the participation of women with disabilities is compared to the participation of either men with disabilities or women without disabilities. On a global scale, the employment rate of men without disabilities is 85%, compared to 75% for women without disabilities; for men with disabilities, the employment rate is 52%, compared to 48% for women with disabilities (Salome et al., 2013). In LMICs, much larger differences are reported between men and women with disabilities: almost 60% of women with disabilities in Ghana are unemployed, compared to 40% of men with disabilities (Naami, 2015).

Employment has three important aspects: obtaining employment, job retention, and employment conditions. For all three aspects, more problems are experienced by women with disabilities in LMICs as discussed in the following sub-sections.

6.2.1. Obtaining and Retaining Employment

Nine studies mention obtaining employment (Gupta, 2013; Kiani, 2009; Lamichhane, 2012b; Moodley & Graham, 2015; Naami, 2015; OHCHR, 2012; Opini, 2010; Ortoleva, 2010) and one study mentions retaining a job as problems for women with disabilities (OHCHR, 2012). Furthermore, even when women with disabilities in LMICs have obtained and retained a job, they have difficulties with employment conditions. Lower than average wages are reported for employed women with disabilities in three studies (OHCHR, 2012; Naami, 2015; Ortoleva, 2010). Little career progression for women with disabilities is reported in two studies (Naami, 2015; OHCHR, 2012) and less interesting jobs for women with disabilities is mentioned in two studies (Naami, 2015; Ortoleva, 2010). Underemployment, related to lower wages, but also to less challenging jobs, for women with disabilities is referred to in one study (Groce et al., 2011).

6.2.2. Employment Conditions

Several studies mention the relationship between employment conditions and other aspects of the lives of women with disabilities in LMICs. Although in most studies the design did not allow for conclusions to be drawn on causal relationships, eight studies make suggestions about the causes of the poor employment status of these women. Cultural stigma—referred to 'stereotyping', 'discrimination' or 'traditional attitudes'—is mentioned in five studies (Gupta, 2013; Kiani, 2009; Lamichhane, 2012b; Naami, 2015). Related to this, Moodley and Graham (2015) report that, in South Africa, black women with disabilities experience discrimination based on the intersection between disability, gender, race and poverty. Moodley and Graham (2015) further explain that women with disabilities experience stigma simultaneously because of disability and (related) unemployment.

Lack of education and vocational skills of women with disabilities is named in three studies (Dhungana, 2007; Naami, 2015; Opini, 2010). Opini states that there is a mismatch between the vocational skills that women with disabilities are trained in and the needs of the job market. In a review on the participation of persons with disabilities in the labour force, Opini (2010) reported that women with disabilities are further disadvantaged because of their gender. In two studies, the consequences of being unemployed are identified. Naami (2015) states that the limited participation of women with disabilities in the labour force results in their limited power and influence in decision-making, both at home and in the community. Moodley and Graham (2015, p. 31) describe the constraints women with disabilities face in terms of their gender, particularly with regard to labour market participation and income.

6.3. Motherhood and Family Life

There are 12 articles that discuss the experiences with motherhood and family life among women with disabilities in LMICs. Braathen and Kvam (2008) underline the needs of women with disabilities in terms of having children and establishing a family. However, women with disabilities are not expected to have relationships and are generally perceived as 'asexual'. Due to such perceptions, they have been denied the roles associated with womanhood, including the role of being a mother (Gupta, 2013). Furthermore, men prefer not to marry women with disabilities, because they are considered incapable of looking after their family. Additionally, there are myths that the presence of women with disabilities can bring bad luck to the family (Dhungana, 2007).

Married life is more difficult to obtain for women with disabilities in LMICs such as Malawi and Ghana, as such women are perceived to be unable to perform the duties of a good wife and mother, according to societal expectations, and, therefore, may not be seen as suitable wives (Braathen & Kvam, 2008; Price, 2011). Kassah et al. (2013) also confirm that women with disabilities are not considered to be capable of living up to female role expectations in terms of housekeeping, parenting, and motherhood. The practice of excluding women with disabilities from intimacy and married life results from the perception that they are either passive receivers of help or patients, or unable to fulfil the duties of marriage or give birth, as mentioned by Morrison et al. (2014) in a qualitative study about women's with disabilities in rural Nepal.

Other authors also report that women with disabilities in LMICs have a low likelihood of becoming intimate and married (Braathen & Kvam, 2008; Emmet & Alant, 2006; Morrison et al., 2014; Parnes et al., 2009; Kassah et al., 2013). According to Kiani (2009), one of the main challenges that all participants in two focus group discussions held in Cameroon shared was finding a suitable marital relationship. One woman stated that many men were afraid of women with disabilities due to the false belief that disability is contagious. Other women felt that African cultural norms expect women to perform household chores while bringing in an income. This places difficult expectations on women with disabilities, who are seen by men as 'unfit' partners (Kiani, 2009).

Besides obtaining a relationship, retaining a relationship it is also a problem for women with disabilities. The reviewed articles indicate a high divorce rate among women with disabilities who were married. If they manage to get married and become pregnant, their pregnancy may become a source of embarrassment. Many women with disabilities become embarrassed and this often prevents them from telling their in-laws about their pregnancy (Morrison et al., 2014). If they do not get married, women with disabilities are afraid of bringing shame on their family if their pregnancy is visible (Morrison et al., 2014). Emmet and Alant (2007) report in their study that women with disabilities are twice as prone to divorce or separation than women without disabilities. Both Braathen and Kvam (2008) and Kassah et al. (2013) found that the majority of women with disabilities in their study were divorced, widowed, or had never been married.

Braathen and Kvam (2008) mention pregnancy as one of the reasons for divorce among women with disabilities, as many men approach women with disabilities with the intention of exploiting them and using them as sex tools, rather than marrying them and having children. This is in accordance with the findings of Parnes et al. (2009), who studied the issues and implications of disability in low-income countries. A survey that they performed in Orissa, India, found that 100% of women and girls with disabilities were physically abused at home, 25% of women with intellectual disabilities had been raped, and 6% of women with disabilities had been forcibly sterilized.

If they succeeded in obtaining and retaining intimacy and married life, become pregnant and experienced motherhood, women with disabilities also experience many other problems. Regarding motherhood, women with disabilities, especially those with cognitive disabilities, have been stereotyped as incapable mothers (Gupta, 2013). Women with disabilities are discriminated against in relation to motherhood because of societal denial of maternity, parenting, and parental rights (Frohmader & Ortoleva, 2013; Gupta, 2013). Accordingly, systemic prejudice and discrimination against them continues to result in multiple and extreme violations of their sexual and reproductive rights, through practices such as forced contraception and/or limited or no contraceptive choices, poorly-managed pregnancy and birth, forced or coerced abortion, the termination of parental rights, and denial of, or forced, marriage (Frohmader & Ortoleva, 2013). The same authors state that the denial of the parental rights of women with disabilities can lead to the removal of their children as:

> Recent data demonstrates that a parent with a disability (usually a mother) is up to ten times more likely than other parents to have a child removed from their care, with the child being removed by authorities on the basis of the parents' disability, rather than any evidence of child neglect. (Frohmader & Ortoleva, 2013, p. 6)

The inaccessibility of health care services also limits pregnant women with disabilities from giving birth by increasing the likelihood of miscarriage and even death. Some sources suggest that women with disabilities also experience denial of maternal health services (Smith, Murray, Yousafzai, & Kasonka, 2004).

7. Discussion

From this review, we can conclude that women with disabilities in LMICs experience huge difficulties with respect to education, employment and motherhood. This concerns both obtaining and retaining the roles (of student, employee, mother), as well performing them. On a personal level, this means that many women with disabilities experience inequality as they are excluded from living the life they would like. Even if not all women with disabilities long for education, employment or motherhood, those who do are deprived of "the right to autonomy and self-determination, i.e., the right of everyone to make free and informed decisions and have full control over their body such as being married and have children—without any form of discrimination, stigma, coercion or violence" (Frohmader & Ortoleva, 2013, p. 2). This right also includes the roles of being a student or employee (Brown, Emerson, Falk, & Freedman, 1971).

The three social roles of student, employee and mother are interrelated. For example, providing disabled women with better education opportunities potentially has a great impact on increasing their employability; some of the reviewed articles found lack of education to be a factor in the low employment level of women with disabilities in LMICs. Consequently, the potential that women with disabilities demonstrate in their education and employment can be proof of their capability to fulfil other social responsibilities, such as married life and motherhood. For example, societies in LMICs generally exclude women with disabilities from motherhood responsibilities, which is one of the most socially valued roles in LMICs, as it is believed that they cannot take care of their children. Meanwhile, showing society that women with disabilities can be educated and employed implies that they can also handle other social roles and responsibilities, such as married life and motherhood. Their limited participation in the labour force results in reduced power and influence in decision-making, both at home and in the community (Kiani, 2009). Moreover, the financial power that women with disabilities acquire from their employment can contribute to the safe growth of their children, especially in LMICs where women with disabilities do not receive any financial support from the government. This, in turn, may minimize the fears men have about marrying women with disabilities with regard to the cost of married life and raising children (Tefera, Van Engen, Van der Klink & Shippers, 2017).

As expressed in most of the reviewed articles, lack of means is an important cause of the low participation of women with disabilities in social roles. Poverty alleviation is stated as an important strategy for minimizing discrimination (Eide & Ingstad, 2011). The link between inequality and poverty can be explained by considering the fact that poor people in LMICs generally lack essential means (such as adequate food, shelter, education, and health care) and access to employment in LMICs is limited. When it comes to women with disabilities, in addition to the poverty that they face alongside other citizens, their gender and disability make it harder for them to compete for the available resources with members of society without disabilities. In other words, the government and society prefer to invest the scarce resources for the betterment of those without disabilities. In some of the reviewed articles, parents were reported to be hesitant to invest in the education of children with disabilities, seeing it as a bad investment, as they believe that children with disabilities do not have the ability to succeed at school and will remain dependent on them whether they send them to school or not. So, there is a lack of awareness among the relevant stakeholders (governments, educators, employers, and families) in relation to the potential of people with disabilities.

Both social role theory and capability approach can be framed as helpful in identifying and analysing the important roles (capabilities) of disabled women. Moreover, the capability approach, in stating that people with less resources are entitled to more means to achieve equal outcomes, can serve as an intervention paradigm. The approach provides the theoretical base for a policy of 'positive discrimination'. This can also play a role in raising awareness of the issues faced by women with disabilities among stakeholders.

Lack of awareness can also give space to cultural beliefs that spark discrimination. For instance, in some communities, disability is considered to be a curse and families of children with disabilities are blamed for the presence of a disabled member, inferring that someone must have sinned and offended God. This moral model of disability takes disability as a defect caused by moral lapse, sin, or failure of faith (Olkin, 2002). Such beliefs may force families to hide their daughters with disabilities. Hence, the need for awareness creation arises (WHO, 2011). Economic empowerment and poverty alleviation alone cannot create a conducive environment for women with disabilities, without also convincing society that women with disabilities have the potential to learn, work and marry. These findings resonate with the concept of intersectionality, which conceives inequality as simultaneously caused by multiple and interactive factors such as gender, class, ethnicity and disability (Björnsdottir, 2010; Meekosha, 2011; Weber, 2001).

The valued roles of student, employee and mother lose some of their significance when it comes to the situation of women with disabilities. For example, giving birth without being married is not socially acceptable and, therefore, being an unmarried mother is a devalued role in most LMICs. But, when it comes to women with disabilities, being an unmarried mother becomes a valued social role, as women with disabilities are not expected to get married.

In general, the studies conclude that participation in important social roles and the achievement of valuable life goals is hampered for women with disabilities due to limited accessibility, stigma and lack of support. Poverty exacerbates this situation, as does discrimination, which hinders women with disabilities from participating and succeeding in these major life domains.

8. Limitations

In this review, the focus on education, employment and motherhood in LMICs does not allow consideration of all the challenges and opportunities faced by women with disabilities. The review may have been more critical and comprehensive if it had involved other important themes, such as health (the availability and accessibility of health centres). Similarly, focusing on LMICs in the search procedure limited the number of articles reviewed, as most of the literature available on these themes is written about developed countries. However, our focus did allow us to unfold issues on accessibility, stigma and support, which are important and intertwined moderators for individuals in achieving their capabilities in education, employment and family life.

9. Recommendation for Future Research

Although the capability approach is a very useful framework guiding our review of the literature, the capability approach in principle suggests that what are essential and valued goals in life can only be articulated by people themselves (i.e., women with disabilities) and cannot be defined by policy makers, politicians or academics. We, therefore, call for research that uses approaches that give room for women with disabilities to articulate their valued goals in life and the opportunities and challenges that affect the accomplishment of these valued goals.

10. Conclusion

The review examined the important challenges and opportunities of women with disabilities in LMICs in relation to their participation in education, employment and motherhood, and the elements that regulate their participation in these important social roles. The theoretical frameworks, SRV and capability approach, helped us to systematically identify and precisely defined relationships among the three social roles of student, employee and mother.

The review found that there is a need to increase awareness and understanding among governments, educators, employers, and families about the life experiences of disabled women in LMICS. If different parts of society are aware and understand the need to fulfil the valued social roles and capabilities of disabled women in relation to education, employment, and motherhood, society will increase the inclusion of women with disabilities by sharing the available resources for the betterment of all citizens. Hence, it is important to develop a better understanding of the lives of disabled women in LMICs in order to minimize the obstacles to equality that they face in participating and succeeding in all valued social roles.

Moreover, governments, educators, employers and families need to understand that denying women with disabilities access to valued social roles deprives them of their basic human rights. CRPD states the need to respect differences and accept disabilities as part of human diversity and humanity, and emphasizes the need for equality and equality of opportunity between persons with disabilities and those without (United Nations, 2006). Furthermore, CRPD clearly requires state parties to ensure that persons with disabilities enjoy legal capacity on an equal basis with others (Frohmader & Ortoleva, 2013).

Our final conclusion from the findings of the review is that there is a need to build a disability component into all aspects of national and international development efforts (Morrison et al., 2014). As presented by Groce et al. (2011) and Frohmader and Ortoleva (2013), the inclusion of persons with disabilities should be a routine part of all programmes that address chronic poverty, because the inclusion of disability in addressing poverty leads to the equal distribution of available resources, which minimizes discrimination against women with disabilities in LMICs in terms of participating and succeeding social roles in education, employment, and motherhood. Moreover, as some of the reviewed articles state, the authorities in LMICs should ensure justice by updating (and implementing) policies designed to minimize and prevent discrimination against disabled women. Furthermore, equal distribution of resources would allow disabled women to develop to their full potential in such a way that they can participate in all domains of life and contribute to their communities and society as a whole.

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Chapter Three

The Disability Paradox: Better Opportunities Versus the Hardships of High-Achieving Disabled Women of Ethiopia

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ABSTRACT

Purpose: This study aims to provide a better understanding of the life experiences of educated disabled women in Ethiopia. The research focuses on opportunities resulting from their disabilities, as well as the role that obstacles play in the lives of successful disabled women.

Method: Qualitative, in-depth, and semi-structured interviews along with personal observations were used to explore the full experiences of participants from their own points of view, as told in their own words.

Results: The analysis was based on interviews with 13 educated disabled women with various physical disabilities. The results of the interviews indicated the hardships faced by high achieving disabled women and the different opportunities that resulted from these hardships (stated as paradoxes throughout the study). The categorized paradoxes consist of: paradox of disability and educational opportunity, paradox of separation from family and success, paradox of hardship in obtaining employment and related opportunities and strength, paradox of disability hardships and self-confidence and self-reliance, paradox of disability and improved quality of life, paradox of support and dependency.

Conclusion: This study highlights how difficult life experiences can be challenging but serves to contribute to the resilience of disabled women in their working life.

Keywords: Disability paradox; Better opportunities of disabled women; Hardships of disabled women; educated disabled women; Ethiopia

INTRODUCTION

A disability can affect a woman at any stage of her life, and its impact is life-long. During the early years, disabled people may need special programs to make education and future career opportunities accessible. At a working age, they may face barriers to participating in the workforce (Lindsay, 2011; Noonan et al., 2004). Inaccessible work environments and the lack of jobs are the major problems disabled women face after they complete their education (Vick & Lightman, 2010). Women with disabilities also encounter barriers to fully participating in other aspects of life, including lack of parental care, misunderstanding by society (Hosain, Atkinson, & Underwo, 2002), and lack of access to medical care (Stein et al., 2010).

Elwan (1999) and Emmet and Alant (2006) documented that disabled women experience higher levels of discrimination and disadvantage than disabled men do. Women with disabilities also experience gender discrimination as well as disabling barriers (Gupta, 2011; Mondejar-Jimenez, Vargas-Vargas, Meseguer-Santamaria, & Mondejar-Jimenez, 2009; WHO & World Bank, 2011). Thus the plight of women with disabilities demands special attention through research such as this that explores their problems related to health, education, employment, violence, family rights, marriage, housing, and participation in public life. This is important in order to disclose the extent of their problems to relevant parties like policy and decision makers (Ortoleva, 2010).

Ingstad, Baider, and Grut (2011) surveyed in their study of living conditions for people with disabilities in Yemen the self-contradictory and false proposition of rejection from prevalent and aspired performance and that of educational opportunities. In Eide and Ingstad (2013), this paradox is stated as follows:

> *More than anyone else, poor girls with disability are bound by traditional family patterns and will easily be left isolated, uneducated and unmarried. Paradoxically, as they may face exclusion from the dominant and desired female role, this also creates opportunities for a few girls who, due to a supportive family, institutional care or other circumstances, may be able to get an education and live an active life because the traditional women's role of entering into married life does not apply to them (p. 4).*

The survey also documented the extent to which the systematic level of the paradox in developing countries exists. Our article attempts to further explore the status of women with disabilities in developing countries. Few studies have actually gone out and interviewed high achieving disabled women in developing countries. The current study explores the status of successful disabled women in Ethiopia. Moreover, the article identifies the situation exhibiting an apparent contradiction in the life experiences of high achieving disabled women in Ethiopia and reinforces the complexity of the phenomenon observed elsewhere. “High achieving” in this context refers to disabled women who are educated at least at the level of a high school diploma and employed.

Disabled women who are educated and employed usually experience difficulties in reaching their current levels of education. Contrary to common belief, the interview results showed that they were often provided with a relatively better chance or opportunity for education, since they are less likely to marry or do other household chores than their non-disabled counterparts. However, disabled women continue to face different problems in education such as access to equipment or devices, and for the visually impaired, access to resources such as readers and interpreters. Securing employment is another difficult life experience for disabled women. After obtaining employment, they continue to face additional problems in accessing facilities, restructuring jobs, changing work schedules, and acquiring equipment or devices.

The experience of overcoming these day-to-day challenges is conducive to strength of character and the development of self-confidence (Alves, 2013). This in turn allows the disabled women to succeed and paves the road for a better quality of life compared to their non-disabled counterparts. (Rutter, 2012) inferred the presence of resilience based on evidence that some individuals have a better outcome than others who have experienced a comparable level of adversity. This article also shows the contribution of challenges to the resilience of the disabled women.

Another paradox that disabled women encounter is related to social support. Social support, on the one hand, helps disabled women to overcome problems; on the other hand, it exposes them to more dependence. Disabled people need assistance, but the level of support should not make them dependent.

In reality, disabled women require a certain level of support for the different problems they face according to the type of disability they have. For example, a blind girl cannot read without Braille and a deaf girl cannot communicate without sign language. This idea is supported by (Yeo, 2001) as follows:

> *In many countries, disabled children are not required to go to school and there is no special provision for their needs if they do enroll. Inaccessibility like public transport, Braille, etc. serve to keep disabled people out, pushed to the margins and without the information they need to participate equally (p. 4).*

This study examines the consequences of the overprotection of disabled women when growing up. A modified version of the grounded theory approach of Starks and Trinidad (2007) is used to help develop an explanation of the experiences of disabled women by means of a qualitative approach of semi-structured interviews.

The educated disabled women in the study were asked about their family background, education and employment history, and the beliefs and attitudes of their society towards disability. While the interview results were coded and grouped into different themes, some components of the paradoxes are identified that may have contributed towards the status of educated disabled women as reported by the majority of the respondents. The observed disability paradoxes are examined in terms of establishing the cause and effect of preventing better opportunities.

OBJECTIVE OF THE STUDY

The aim of this paper is to identify and document the life experiences of educated disabled women in Ethiopia. It analyzes how societal expectations present additional challenges. Moreover, it explores other social obstacles facing disabled women. The paper identifies data gaps in existing literature, leading to a more sophisticated discussion of the role that hardship plays in the creation of opportunities and, consequently, opening the door to future studies in this area.

CONTEXT OF THE STUDY

The study involved an exploration of educated disabled women's life experience in Ethiopia. The population of Ethiopia has increased steadily over the last three decades, from 42.6 million in 1984 to 53.5 million in 1994 and 73.8 million in 2007 (CSA, 2011). Ethiopia is one of the least urbanized countries in the world; only 16 percent of the population lives in urban areas (CSA, 2011). According to the International Labor Organization ILO (2011), seven to ten percent of the population has a disability, and the vast majority of people with disabilities live in rural areas where access to basic services is limited (CSA, 2011). A survey on disability in Ethiopia (ILO, 2004) reported that 60 percent of persons with disabilities of working age were unemployed in 1995, of whom some two-thirds were self-employed in rural areas in occupations such as agriculture, animal husbandry, or forest activities. Begging is often a means of survival in urban centers, in addition to assistance from religious institutions and charities (ILO, 2004). In Ethiopia, disability and begging are traditionally linked (Groce et al., 2013).

METHODOLOGY

The primary methodology was the use of in-depth, semi-structured interviews based on those used in previous studies such as Career Development Notable Latinas (Gomez et al., 2001) and Highly Achieving Women With Physical and Sensory Disabilities (Noonan et al., 2004). The questions were tested and refined through a pilot study prior to conducting the interviews. The pilot test was conducted with seven women with physical disabilities located in the Addis Ababa metropolitan area. This was consistent with the goal of qualitative research to allow participants to describe their experiences from their own perspective and in their own words (Morrow, 2005). These pilot interviews were not included in the final study but were used to modify the interview questions. The interview covered the following areas: family background, educational experiences, employment opportunities, and the beliefs and attitudes of the society towards disability.

Participants included 13 educated disabled women with various physical disabilities. The interviewees lived in the Addis Ababa metropolitan area of Ethiopia. Because the number of vocationally successful women with disabilities in Ethiopia is small, snowball sampling was used to select disabled women for the structured interview. Six of the 13 interviewees have graduate level education, three have undergraduate degrees, and of the remaining, three have associate degrees, while one has a high school diploma. All of the interviewees currently hold jobs. Four of them are project coordinators and facilitators, three are accountants, two work as secretaries and cashiers, two are high school teachers, one is a system administrator, and one is a budget analyst.

Participants were contacted initially by visits to their workplaces and then by telephone calls with a description of the study and an invitation to participate. Those who agreed to participate received a letter and brief information about the interview. Participant interviews were conducted by the first author and took place at a site of the participant's choice (with some interviews held in the interviewer's car). The interviews took between 1 and 2.5 hours each, and the average duration was about 1.5 hours. The interviews were performed in Amharic (the native language of both the interviewer and interviewees). The interviews were audio-taped for later transcription and analysis. At the conclusion of the interview, field notes were completed by the interviewer (author) on the interview location, length of the interview, perceptions of rapport, and other interview characteristics (e.g., interruptions). The field notes were used in interpreting transcripts as well as during data analysis to assess the trustworthiness and legitimacy of the narrative data.

Data analysis was conducted using a modified grounded theory approach (Starks & Trinidad, 2007), in which a theory is generated through a series of steps that proceeds from data collection to coding of data into concepts; to categorization of concepts into increasingly comprehensive aggregates of categories, or constructs; to descriptions of categories based on their properties and dimensions; and finally to the articulation of a theory in which the emergent constructs and their interrelationships are described. The grounded theory practice of theoretical sampling, in which data collection (including continual interview revisions) and data analysis proceed simultaneously, was modified in this study by identifying a diverse sample at the outset, based on *a priori* criteria (Patton, 2002) and administering the same interview protocol to all participants.

Our analytical approach is consistent with procedures established by Burnard (1991) and Lavelle and Dowling (2011). We largely followed their methodology for analyzing semi-structured open-ended interviews (See Footnote 1 for details of the methodological approach).[1]

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[1] In this study, interviews were recorded and then transcribed verbatim and translated from Amharic to English by language professionals who checked the meanings of the translations by the author. The first stage involved taking notes after each interview and using them as "memory joggers" (Burnard, 1991) during the initial analysis phase. The second stage

HARDSHIPS FACED BY HIGH ACHIEVING DISABLED WOMEN

In Ethiopia, disabled women pass through many hardships from early childhood. To start with, they are treated like outcasts by society because their disability is believed to be the result of wrongdoing by their families (Simkhada et al., 2013); (Getachew, 2011). The beliefs and social perceptions about disability often result in the dislocation of the disabled from their places of birth, and they become deprived of the opportunity to live with their families. One interviewee articulated the reason for her isolation from her family as follows:

> *For example, the reason why I did not grow up with my family is because of my disability. So, my physical disability deprived me of living with my family. I grew up in an institution… (Interviewee 2)*

Another woman described her disconnection from family as follows:

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involved reading through all the transcribed interviews while making notes on descriptions given. The third stage focused on open coding and involved re-reading the transcripts. The list of open codes was then examined more closely, and those that were similar were collapsed into broader categories (stages four and five). In stage six, the coauthor of this paper, who was not part of the interviews, examined three interview transcripts and identified a category system. Similar themes were also identified by the interviewer. The aim of this step was to enhance the validity of the categorization process (Burnard, 1991) Lavelle & Dowling, 2011) and to enhance the study's validity. The transcripts were then examined again in light of the themes generated, and themes were distinguished in the text using a color coded system.

The text from the transcripts was then reorganized under the themes, with attention to context maintained by working alongside complete copies of each transcript (stages 8-10). Three study participants were invited to review their transcribed interviews and make notes on the main points that emerged during the interview (stage 11). These were then compared to the themes and categories identified in the analysis. All of the sections were filed together for direct reference when writing up the findings. Copies of the complete interviews were kept close to the authors during the write-up stage, as were the original tape recordings. Whenever anything appeared unclear during the write-up, the researchers referred back to the transcript or the recording. Once all of the sections were together, writing began, which constituted stages 12 and 13 (Burnard, 1991).

> *….I neither lived with my family nor do I have a person to live with in general. Generally, I am isolated and live by myself. This resulted in lots of problems in my life. (Interviewee 5)*

The above excerpts show that physical disability is normally the direct cause of the disabled people's separation from their families, which in turn presents them with more problems. This can be viewed as a result of society's perceptions of disability.

In Ethiopia, disabled girls live far away from their families because of social influences such as a negative perception and beliefs about disability that force parents of the disabled to send their children away to cities, either to an institution or to live with relatives. The following excerpt from an interview with one disabled woman helps to clarify this:

> *When my family knew that my disability is beyond cure, the stress killed my mother. It was like my family is condemned. I was told that people said that my disability was a curse. "What did the family commit to deserve this?" they asked. Imagine my mother had died and there was one child in the family with physical disability and there was no education. (Interviewee 2)*

In this excerpt, the interviewee also shares the beliefs of the society in associating the death of her mother with her disability. Another interviewee confirmed this idea as follows:

> *Every time a child is born an animal is slaughtered, either a chicken or sheep (Certain gods were offered sacrifices in the form of animal sacrifices for the purpose of appeasing those gods seeking counsel and blessings). But when my mother had a child, my grandmother was poor and she didn't know that her mother did slaughtering for this kind of purpose. Since she didn't know that my great grandmother did this and because she didn't have that much money she didn't slaughter immediately. After some time, my grandmother had a dream, and she told me they (the gods) said, "Was it better to take out money for the hospital for your granddaughter, or to slaughter one chicken?" As a result, I lost my sight... (Interviewee 7)*

The above statement shows that even some of the educated disabled women continue to believe that their disability resulted from failing to comply with the rituals. It suggests that cultural values are very important and that the education provided does not address these types of cultural norms around disability.

One facet of Ethiopian culture that some may consider chauvinistic is that most women in rural areas of Ethiopia perform the household duties by themselves. However, when it comes to disabled women, they are considered burdens to their families even when they carry out the various household chores. Their families do not value the chores the disabled children perform as worthy. The president of the Ethiopian disabled women association puts it as follows:

> *If you ask parents what their disabled daughter does, they would say, "She doesn't do anything, she doesn't work, she is not educated. What could she do?" But they give her 90 percent of the work in the house. She prepares "wot" (staple sauce dish in Ethiopia) sitting down right there, grinds coffee (by pounding roasted coffee), washes clothes. Everything is brought to her to do, but her efforts are not considered. They say she doesn't do anything since doing the house chores is not considered work…. She spends her whole day bringing water not only for her family but also for the neighbors. She does this because she thinks that is the right thing to do. The ones who encounter this kind of thing are the female ones. Girls face more problems than disabled boys.*

This shows us that, in developing countries such as Ethiopia, the constructive awareness by parents of disabled children about issues and concerns of people with disability is low, as interviewee 3 corroborates below.

> *I was not that good at communication because I did not go through a life that encouraged that. I have told you that my family wanted me to always stay and sit at home. And I used to stay at home the whole day, sitting alone in a corner. My family sometimes even used to lock me inside the house, fearing that a thief might enter the house and steal. I did not ask them why they did that. But I used to cry a lot... I often wonder, how would they think that I might not understand as a thief entered while I am there? As I told you, I was like a second citizen in that house so I did not have the strength or the right to tell them not to do that.*

In general, women in the rural areas of developing countries such as Ethiopia do not usually have access to educational opportunities. Literature shows that educational opportunities have been improving in developing countries, although the opportunities are still limited (Lewin, 2009). For disabled persons, finding educational opportunities has become even more difficult than it is for others since they are the least expected to enroll in school and the infrastructure makes facilities inaccessible. As Groce (2004) observed, sending disabled children to school, including them in social interactions, and preparing them for participation in the adult world seem unnecessary.

The other problem disabled women encounter is finding employment, as illustrated in the excerpt below:

> *It was tiresome to get a job… and even more difficult for physically disabled people. You have to apply for a job in several places before you are considered for a job. Even when hired, my employment is not considered by merit but out of fear of God. (Interviewee 2)*

This above citation demonstrates that disabled women are required to make an extra effort to secure employment, and once employed they suffer from a perception that they got the job due to fear of God on the part of the employer(s) or societal guilt. Some employers use recruitment exams and interviews to discriminate against disabled job candidates, as captured in the following excerpt:

> *I applied to work for many companies that I thought could be related with my credentials, but I was repeatedly told that I failed the recruitment exam. (Interviewee 1)*

This suggests that the interviewee considers her disability as the underlying reason for not being considered. Another interviewee witnessed that sometimes employers explicitly tell disabled job candidates that they do not meet the hiring criteria due to the impairment, as in the following case:

> *Let me tell you my own history. I competed for a position of ticket officer. Although it is not such a difficult job, I was told that I could not do the work because of my disability. Such incidences are common. (Interviewee 12)*

Often, educated disabled women may not find employment opportunities, and if employed, it may not be in their own profession, as expressed below:

> *Very few disabled educated women find a job, and often they stay home. Although educated, I have many friends who are forced to take non-professional positions. (Interviewee 9)*

Once employed, disabled women have to prove to employers that they can perform as well as able-bodied employees, as captured by the following response:

> *When I am employed, I am subjected to undue stress because of preconceived bias towards disabled people not performing well. What can I do to change pre-conceived views? If they are not satisfied by my performance, would they link that with my disability? (Interviewee 3)*

This in turn may result in less pay, as stated below:

> *They hired me as an assistant teacher with less pay than what is set for the position. I performed equal to or better than my colleagues. Although I worked for a religious institution where equality should have been the norm, this was not the case. (Interviewee 13)*

This excerpt shows that at times the employed disabled women work for less pay doing equal work compared to non-disabled employees with the same capacity. The employment experience of disabled women is often frustrating, as discussed below:

> *I am often reminded by others that the job is difficult for me because of my disability. People think that my guide is doing everything for me and they don't seem to acknowledge my work. This negatively impacts my work morale. For example, I always worry that if I fail to do things to their satisfaction, my employers will interpret that it is because of my disability. (Interviewee 3)*

The interviewee here implies that she worries about acceptance by others around her. She is also expected to do things at the satisfaction level of others and she feels that any failure will be attributed to her disability.

The above excerpts of life experiences of disabled women in Ethiopia provide a window into the magnitude and scope of socio-economic barriers faced by disabled women. Nevertheless, the experiences of educated disabled women in Ethiopia also seem to create more opportunities than seen by their uneducated counterparts, as discussed in the following section.

PARADOXES

In this section, the paradoxes encountered in the lives of educated disabled women are explored. To begin with, the educational opportunities offered to disabled women due to their social exclusion are discussed. The perception of society towards disabled people resulting from the separation from their family appears to instill traits of success. The strength, self-confidence, and independence they develop through the hardships of their life experiences are also documented. It also shows the resilience of the disabled women in their working life. As a domain of inquiry, resilience science in human development refers to the study of the processes of, capacity for, or pathways and patterns of positive adaptation during or following significant threats or disturbances (Masten, 2011:494). The paradox of disability leading to a relatively better quality of life is also discussed. The paradoxes are presented using quotes from the experiences of high-achieving disabled women in Ethiopia.

Paradox of Disability and Educational Opportunity: Some disabled women in Ethiopia obtain certain institutional benefits because of their disability, as described below:

> *My father had a distant relative in Addis Ababa who worked near the Ethiopian Association of the Blind and told my father that I could be educated. Through her assistance, I was enrolled in a boarding school for visually impaired at a young age. That opportunity is the foundation for my success in life. I was the only one who was educated from among my family members. (Interviewee 3)*

This excerpt shows that the educational opportunity the interviewee obtained was due primarily to opportunities created only for disabled children. This concept was further articulated by another interviewee as follows:

> *I don't think I could have been educated and been in a better position if I were not disabled. I can say this because when I see my non-disabled brothers and sisters, I am the only one who was educated. But my elder siblings are all married and did not have the educational opportunities that I was privileged to receive. (Interviewee 2)*

Women in the rural areas of Ethiopia are mostly forced into marriage without education. But disabled women are not considered for marriage, and this creates an opportunity for them to go to school. Educational opportunities separate disabled women from their families at an early age. This also results quite often in relocation from rural to urban settings in order to access education.

Paradox of Separation from Family and Success: Disabled women move to metropolitan areas of the country for education, and paradoxically, this separation seems to inspire disabled women to succeed. One interviewee explains this situation as follows:

> *[When] I went to the rural area after I was educated, I met my father, who told me that my mother died and he was left to raise my other siblings by himself. He also said that if I had been left with my family, this wouldn't have happened; I wouldn't be the success I am today. Although it was to redeem himself of guilt, he was right! ... Others such as my aunt said, "Your father told us that you are educated and successful. Sometimes we thought you were not alive." (Interviewee 2)*

The interviewee stated that even though it is difficult to be removed from family, it did bring her success. The interviewee further explained that when she became independent, she started thinking of what life could have been like if she had been left with her family:

> *Later when I became self-reliant, when I heard what my siblings said about their experience at home..., I realized what could have been my life if I had been left at home, although I missed out on knowing my parents then. (Interviewee 2)*

The interviewee missed out on her family love. However, the separation from family made her inspired and successful.

The adversities do not end for disabled women after their success in education. The challenges of employment persist, and the strength developed as a result of the sustained adversities is discussed in the following section.

Paradox of Hardship in Obtaining Employment and Related Opportunities and Strength: Although educated disabled women have to pass many hurdles to become employed, many do find jobs. One interviewee described her experiences as follows:

> *I got my first job because I was a person with disability. At the time, I was doing nothing because I couldn't find a job. Then, there was a vacancy that was*

> *advertised needing a visually impaired person. Overall, I benefited from my disability to get the job. The job enabled me for training, travel abroad, and accumulated experience. I enriched my resume, and that furthered my chances for opportunities in higher studies abroad. (Interviewee 3)*

This excerpt suggests that the difficulty of securing employment and the limited opportunity for physically disabled people is an exception, not the rule. Despite the challenges, all the disabled women interviewed in this study appear to be confident and hard-working individuals, as stated below.

> *In order to survive what I was dealt by my disability, I focused on my education … [That] also made me realize that I have to do it on my own. Sometimes people tell me what I have is enough, and they don't understand my effort to further improve myself in education… [That] helps me realize that being physically disabled has become an inspiration for strength. (Interviewee 2)*

Disability and the limited support system has become an incentive for hard work and self-reliance. Those interviewed here who succeeded in careers tend to strive to help other disabled women, as one of the interviewees explained:

> *We organized a physically disabled women's association with eight of my friends… I graduated in IT, and now I am an expert. I am a high-level expert in information communication technology. I got here through promotion after starting from a lower level. But I am focused more on the physical disability thing. I want to be an example for those people to get beyond their physical disability and be strong. (Interviewee 2)*

The continued adversities that disabled women are subjected to made them strong. The women interviewed in this study also regularly reported that they developed good work ethics due to the efforts they made to prove themselves to employers and colleagues that they could perform. Moreover, they organized themselves to help others and became role models for the others. The trials and tribulations of their disabilities helped them to develop self-confidence and self-reliance.

Paradox of Disability Hardships and Self-Confidence and Self-Reliance: Self-reliance for women in developing countries is generally difficult. For disabled women it is even worse. Paradoxically, many of the women in this study felt they had achieved self-confidence and become self-reliant, unlike their female siblings who were dependent either on their husbands or on their family members. One disabled woman who met her family after she became successful articulated the effect of her self-reliance and self-confidence on her family as follows:

> *My relative saw the self-confidence and how self-reliant I was when she came to my house. ... Before that visit, she depended more on my brothers rather than me. My brothers are not physically disabled. ...[It] was me whom everybody had looked down on, the one who everybody thought won't become anything. But it is me now who has graduated and is self-dependent. She said I am disabled but completed school, and she looked at my brothers as inferior when compared to me. It became the reverse…Nobody noticed me before, but my situation made me a success. (Interviewee 2)*

The above excerpt shows that the success of disabled women can even improve the views of family members towards disability. The self-confidence these women developed was the result of sustained efforts to manage their disability. The challenges faced from childhood to the present helped them develop the ability to solve problems. One interviewee explained this as follows:

> *My self-confidence evolved over time. During my graduate studies, I asked for help with things that I wasn't able to do in a relaxed manner without being worried. (Interviewee 4)*

The disability experience brought incentive to find solutions to their problems. One interviewee stated that she could not have developed the level of self-confidence had it not been for her disability experience, as follows:

> *I do not think or see that I could do better if I were not disabled. I could have, maybe, thought of it like that in the past but now I do not believe I could add anything to the things I could do and think had I not been disabled. I think I could do all things that other people at my level could do. (Interviewee 4)*

The experiences disabled women in this study were subjected to helped them to believe in themselves and realize that they could do what others could, thereby increasing their self-confidence. In addition to this, they became self-reliant, which they could not have achieved had they not been disabled. The urban life also improved their quality of life compared to those who lived in the countryside.

Paradox of Disability and Improved Quality of Life: The lifestyle of women in the rural areas of Ethiopia is generally difficult. Interviewee 3 articulated it like this: *"By the way, I am truly a lucky person. The life of many people is not like this. I am very, very lucky.*" Paradoxically, the disabilities of some created improved opportunities in life, as explained by another interviewee as follows:

> *For example, if I were in the rural area, what would have happened to me? I would have stayed at home and my other job would have been brewing coffee and nothing more of value. Then, when your parents separate from you, maybe by death, you can't go out there and be self-reliant… (Interviewee 2)*

Some of the educated disabled women helped their siblings to become educated. An interviewee articulated this experience as follows:

> *So, if I had not learned, my life would have been what most other people expect. Maybe I would have been found at the lowest level of life. I have helped myself and others. For example, I have helped two of my nephews through high school and allowed them to stay with me and join the University this year. I personally help other people like this too. (Interviewee 3)*

This excerpt explains the extent to which the woman went to help her non-disabled siblings. Beyond this, the same interviewee stretches herself to help her community:

> *I was born in the rural area and my family still lives in poverty in the community, and I want to start a program that helps my community. Before starting that work, I want to develop the capability to fulfill my vision effectively. But until then, this is the ladder that will make me reach there. Do you understand? I didn't find it as a job that you just get up at one point and do... But, whatever the case, my vision is to do something that reduces poverty. (Interviewee 3)*

According to the interviewees, the hardships have ameliorated their circumstances compared to those of their non-disabled family members who are still leading poor lives in rural areas. Many aspire to help their families and communities.

Paradox of Support and Dependency: The experiences of the women in the study suggest that the level of support provided to disabled people should be limited to the extent that cannot discourage them from doing things by themselves. Otherwise, the support will be more like overprotection, which might discourage disabled people from handling responsibilities by themselves and from developing their careers properly. The negative effect of too much support from families of disabled women hindering the disabled from achieving success is best presented by the following excerpt from a partially blind woman:

> *I could see a little. So I used to go to school and come back with the children in my neighborhood. It was a small town and my father was well known there. So other children's notes were given to me. I also had a tutor at home who read to me and helped me with my homework. My parents did not encourage me to read with Braille. I should have also done my homework by myself. It is not good to be overprotective. It hindered me from working on my own. I relied on others for support and that hurt me. (Interviewee 6)*

Support becomes an obstacle when it reaches the level of overprotection, described as over-facilitating activities, which makes one dependent (Field & Hoffman, 2002; McDonald & Kidney, 2012; Hawkins, Redley, & Holland, 2011; Thompson, Galbraith, Thomas, Swan, & Vrungos, 2002). These authors articulated this concept as care at the level of restricting the autonomy of a person, which emphasizes the dependent role of the recipient. The same idea is articulated by one disabled woman as follows:

> *I grew up in a rural area where people are very conservative. You are not to speak loudly and girls are expected to go to the back when a guest comes ... especially me. When others would go to the river, herding or to play with each other, or go to a far place, I couldn't do that. Even if I wanted to go to some distant place, I would be told that I will fall into a ditch or that a thorn would wound me. For those reasons they wouldn't let me out of the house. In addition to that, for example, I couldn't even bend to pick up my shoes. Instead, they were the ones who handed them to me. All the things they did made me dependent and its influence has made me a shy person. ... I am very shy. If you tell me to go to an office to talk about anything, unless it is something that I must do, I am very afraid. What I think in my heart and what I actually say are not the same. And this is my family's influence because they didn't tell me to be strong. (Interviewee 5)*

The quotation implies that the cultural norms of the society affect the socialization of girls. When these norms are implemented in the lives of disabled girls, it restricts them from performing different activities and sometimes can make them shy, as was mentioned in the excerpt. The same interviewee stressed the influence of her family on her social life as follows:

> *Related to family influence, for example I prefer to read a book, if there is one nearby, than to talk to staff there. Rather than chatting with them or going to some place, I would prefer to have a computer and write something. I think it may be the influence of my family. The fact that my family said stuff like, "Sit down, don't do that" I think has influenced me. Being with my colleagues doesn't make me that happy. (Interviewee 5)*

This interviewee shows the adverse influence of her family on her social life while another interviewee described the effect of overprotection as follows:

> *The teachers at my school used to say that Mr. X's daughter is sick… Even if I did something wrong, they let me pass my tests saying that I was sick. I did not go through most of the challenging things on my own. (Interviewee 6)*

As stated in the above excerpts, overprotecting disabled children can lead them to failures such as relying on others for support, being shy, and being lonely. On the other hand, failure, prevention, and discouragement were found to create better results in terms of their achievements. In relation to failure, one interviewee explained it this way:

> *The other children who did not get passing grades got employed in cafes and went to Arab countries and they used to do small things. I was the only one without a job while some of the people I knew used to do something. I realized that I could not be employed in shops or anywhere else. What is considered the last resort was being hired as a maid. Right? It came to my mind that I could not do that. So, I studied hard and took the exam privately. I passed and then entered Addis Ababa University. (Interviewee 6)*

This excerpt indicates that disability can prevent people from carrying out some duties. Even if they cannot succeed in their education, non-disabled women may have plenty of opportunities to generate income. But for the disabled ones, finding work is more difficult, and this issue forces them to stick with their education and study hard.

Interviewees stated that barriers that are associated with their disabilities (like fear of failure and judgment by non-disabled persons) hurt them. Generally, women report greater fear and are more likely to develop anxiety disorders than men (McLean & Anderson, 2009; Sagar, Boardley, & Kavussanu, 2011). Here we might assume that fear of failure affects disabled women more. But the interviewees believe that this helped them to develop the determination to perform better and to have plans and visions for their lives.

CONCLUSIONS

This study documented the experiences of a select group of educated high-achieving disabled women in Ethiopia using in-depth, semi-structured interviews. The interviews capture how disabled women are viewed by society. The study sheds light on the belief that their disability is the result of wrongdoing by their families. These beliefs and traditions have unintended consequences for disabled women such as dislocation from their places of birth and separation from family. Most interviewees also shared issues with finding jobs, problems of access to the technology they need to perform, and when employed, the extra effort required to prove themselves to employers and co-workers. These adversities tend to create resilience in the interviewees.

The issue of educational opportunities not being available for disabled women's able-bodied siblings in rural areas may well be an exception rather than the rule. However, the continued challenges such women faced due to their disability inspired them to reach high levels of education.

The women interviewed in this study also regularly reported that they developed good work ethics due to the efforts made to prove themselves to employers and colleagues that they could perform.

It appears that the disabled women believe that the struggle they experienced in shaping their lives has made them confident and self-reliant.

According to the interviewees, the hardships have ameliorated their circumstances compared to those of their non-disabled family members who are still leading poor lives in rural areas. Many aspire to help their families and communities.

The interview results also suggest that too much support from family members can make disabled women dependent, while prevention/exclusion can make them stronger, although they also felt deeply hurt by their family, colleagues, and/or the society.

This paper identifies data gaps in existing literature, hopefully leading to a more sophisticated discussion of the role that hardship plays in the creation of opportunities and, consequently, opening the door to future studies in this area.

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Chapter four

The grace of motherhood: disabled women contending with societal denial of intimacy, pregnancy, and motherhood in Ethiopia

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ABSTRACT

This study aimed to provide better understanding of intimacy and marriage, pregnancy, birth, and motherhood experiences of women with disability in Ethiopia. Qualitative, in-depth, and semi-structured interviews along with personal observations were used to explore the full experiences of participants, as told in their own words. The result of the interviews indicated that relationships and motherhood proved a very rewarding option for women with disabilities. They also expressed their need for intimacy regardless of society's denial. Challenges identified include negative societal attitudes toward women with disabilities regarding relationship, pregnancy, and child-rearing. Accessibility of health centers in addition to the ignorance and negative attitudes of the physicians are also reported to be major challenges for the interviewees. This study highlights how rewarding the experience of motherhood was for the interviewees and also shows that women with disabilities face challenges at every step of their experiences, because of society's prejudices toward disability.

Points of Interest

- This paper reports on Ethiopian disabled women's experience on intimacy, pregnancy and motherhood.

- Interview data revealed that mothers experienced significant challenges with regard to accessibility of health centers, physician's lack of knowledge about and problematic attitudes toward them and more general societal prejudices towards individuals with disability.

- The interview data showed that the experience of intimacy and being empowered women.

Introduction

The desire to have children has customarily been elucidated by the existence of 'the maternal drive': motherhood is often reflected as a typical part of every woman's female identity (Haelyon, 2006; McQuillan, Greil, Shreffler, & Tichenor, 2008). Furthermore, one of the major social roles that is expected from women is motherhood (Poole, Hare, Turner-Montez, Mendelson, & Skipper, 2013). Although this expectation is a worldwide injunctive for women (Kallianes & Rubenfeld, 1997), in the modern western world motherhood has become more 'optional' (Prilleltensky, 2003; Thomas, 1997). In the culture of developing countries motherhood is not viewed as optional; rather, society strongly expects women to marry and have children.

However, the majority of disabled women globally are denied the possibility of intimacy or marriage (Frohmader & Ortoleva, 2013) and are commonly perceived as asexual (Malacrida, 2015; Price, 2011; Wickenden, Nixon, & Yoshida, 2013). Most people in developing countries tend to believe that disabled women cannot be involved in relationships and have children. Women with disabilities in developing countries are particularly vulnerable to socially constructed misconceptions (Anastasiou & Kauffman, 2011) regarding the impossibility and/or inability of being involved in relationships and experiencing pregnancy and motherhood. In some cases women with disabilities may get pregnant due to sexual abuse (Kvam & Braathen, 2008). Sexual violence is a profound human rights violation and public health concern (Dartnall & Jewkes, 2013). Nevertheless, women with disability that do become mothers often do experience motherhood as a blessing. This is to some extent also true for women who became pregnant as a consequence of sexual abuse (Malacrida, 2009).

Furthermore, disabled mothers are often viewed as incapable of handling a maternal role; they are in many ways denied children and derided as mothers (Kocher, 1994; Price, 2011). Thus, many disabled women are considered as being unable to live up to traditional role expectations for women in society. They are less likely to get married than other women (Groce, 2004), highly vulnerable to divorce, and frequently raise children as single mothers (Kassah, Kassah, & Agbota, 2014). During pregnancy women in developing countries experience negative attitudes and behavior of society (Prilleltensky, 2003) and of professional caregivers (Bremer, Cockburn, & Ruth, 2010; Smith, Murray, Yousafzai, & Kasonka, 2004; Walsh-Gallagher, Sinclair, & Mc Conkey, 2012). Accessibility of the health centers is also a challenge for pregnant disabled women (Smith et al., 2004).

Yet, in a previous interview study on educational and employment opportunities of disabled working women in Addis Ababa (Tefera & Van Engen, 2016) we were struck by the empowerment that mothers exhibited as they talked about motherhood in the interviews. Although in a society such as Ethiopia be(com)ing a mother when being disabled is considered hardly conceivable, most of our interviewees actually *were* mothers, and very proud of it too. The grace that motherhood gave our interviewees instigated us to delve deeper and go back to our interviewees and conduct additional interviews to probe more to their experiences of intimacy and marriage, pregnancy and giving birth and their experiences of motherhood.

Objective of the study

Most of the developing countries' literature on disability has focused on social, economic, and health problems. This paper aims to show the experiences of women with disabilities by focusing on their need for intimacy and marriage, how they enjoy their pregnancy period while also facing challenges, and how they manage their motherhood responsibilities and take pride in it. We analyse how social roles and expectations present additional challenges. Moreover, the paper identifies and documents experiences of intimacy and marriage, pregnancy and giving birth, and motherhood experiences of women with disabilities in Ethiopia. Below we first describe our grounded methodological approach, our sampling procedure, the context of the study and the steps of our data-analysis. Then we present our findings thematically. We first discuss how societal expectations can disrupt experiences of intimacy and marriage life, then we discuss the different challenges faced during pregnancy and giving birth and finally discuss the many facets of motherhood experiences, both in how motherhood aggravates challenges and at the same time empowers and prides women with disabilities. In the discussion we reflect on our findings from a capability approach (Nussbaum, 2006; Robeyns, 2005; Sen, 1999), a (family) quality of life approach (Brown & Faragher, 2014), and a disability-culture perspective (Kirsbbaum, 2000; Kuppers, 2011; Peters, 2000; Ripat & Woodgate, 2011).

Methodology

The approach used was purely inductive (Knox, Mok, & Parmenter, 2000). In our previous study focusing on the opportunities and challenges women with disabilities had due to their disability in relation to education and employment (Tefera & Van Engen, 2016), those who were mothers strongly and repeatedly discussed the empowerment they gained through their motherhood experience. Their stories revealed that becoming involved in an intimate relationship and/or marriage is not a matter of due course and neither is pregnancy, giving birth and motherhood. The themes were intertwined and thus in our second study we probed more on these three aspects of disabled women's experiences. While selecting additional interviewees other than who were involved in the previous interviews, we preferred to choose again employed mothers with disabilities for consistency. Education and employment offer women opportunities to pursue capabilities that they value in life, and, as we found in our previous article, these capabilities are opportunities to pursue happiness in marriage and satisfaction with their role as mothers.

As analytic approach we used qualitative methods that relied on data obtained from face-to-face interviews. The primary instruments were in-depth, semi-structured interviews and personal observations, which allowed exploration of the full experiences of participants' own points of view as told in their own words.

The 13 participants were employed women with physical or visual disabilities, and the interviewees were from the Addis Ababa metropolitan area, Ethiopia. The women experienced different types of disability; they were blind, or partially blind, some of them had 'leg impairments. Leg impairment is generalized in this way as some interviewees were not sure about the type of their disability except that they have some kind of leg impairment. Of the interviewees with leg impairment, one uses a wheelchair and the others use crutches. Disability may be caused by many factors, such as birth defects, malnutrition, diseases, inadequate medical care.

Snowball sampling (Sheu, Wei, Chen, Yu, & Tang, 2009) was used to select employed disabled women. Interviews were conducted by the first author and took place at a site of the participant's choice. Five of the interviewees were interviewed twice. These women were interviewed for a longer time for the article on educational and employment opportunities (Tefera and Van Engen, 2016) and interviewed for a shorter interview on their motherhood experiences a second time. Eight other interviewees were interviewed specifically for this study.

In general, interviews took approximately 30 minutes to 1 hour, with an average duration of about 45 minutes. The interviews were performed in Amharic (the native language of both the interviewer and interviewees). The interviews were audio-taped for later transcription, translation, and analysis. At the conclusion of the interview, field notes were completed by the interviewer (first author) on the interview location, length of the interview, perceptions of rapport, and other interview characteristics (e.g., interruptions). The field notes were used in interpreting transcripts as well as during data analysis to assess the trustworthiness and legitimacy of the narrative data.

Context of the study

Ethiopia is Africa's second most populated country, with 85 million people (Aguilar, Carranza, Goldstein, Kilic, & Oseni, 2014). Although it is difficult to get an accurate figure for disabled people in developing countries (Eide & Loeb, 2005), five million people are reported to live with a disability in Ethiopia (Groce et al., 2013). The health services coverage in Ethiopia is one of the lowest in the world. The potential health services coverage (PHSC), for instance, was limited to 51.2% of the population in 2000/01 (Demeke, Guta, & Ferede, 2003). The coverage is biased toward urban areas and features low service coverage for women (Woldemichael & Tenkorang, 2010). Moreover, an increasing number of medical doctors of Ethiopia works abroad because of high level of remuneration they get in the western countries. For example, there are more Ethiopian medical doctors in Chicago than in Ethiopia (Aarts & Itansa, 2016).

Data analysis

The analytical approach is consistent with procedures established by Burnard (1991) (Lavelle & Dowling, 2011; Tefera & van Engen, 2016). Burnard (1991) proposed a 14-stage method for semi-structured open-ended interviews but also suggested that the method could be modified when "more clearly structured interviews" are used as is applicable in this study, similar to those used by Lavelle and Dowling (2011) and Tefera & van Engen (2016).

In this study, interviews were recorded and then transcribed verbatim and translated from Amharic to English. The first stage involved taking notes after each interview and using them as "memory joggers" during the initial analysis phase. The next stage involved reading through all the transcribed interviews while making notes on descriptions given. Next was focusing on open coding and involved re-reading the transcripts. All four authors examined four or five interview transcripts each (together all 13 interviews) and identified themes and a category system. The transcripts were then examined again in the light of the themes generated by the first author and two trained colleagues, and themes were distinguished in the text using a color coded system.

The text from the transcripts was then reorganized under the themes with attention to context maintained by working alongside complete copies of each transcript. These were then compared to the themes and categories identified in the analysis. All of the sections were filed together for direct reference when writing up the findings.

Findings

In the following excerpt the interviewee describes a discussion between her and a man who gave her a car ride, capturing the beliefs in society about the intimate lives of disabled women:

> *He asked, "Is he your husband?" I said yes. "How did he marry you?" "Why wouldn't he marry me? I have also married him," I said. This created a lot of questions in him. He was even driving at a very slow speed to continue the conversation. He said it is very astonishing. I said, "Why? I am actually the one who needs to be admired." He said that what he meant was the fact that he married me. I said, "I have also married him," and I was laughing a lot because the man was very astonished by this. He then said, "OK, let me ask you one question: How can you sleep together?" I said, "If it surprises you, I have two children." He said, "You were pregnant?" "Yes," I said. "How did you get pregnant?" Again I said, "Is it with my legs that I get pregnant? What is wrong with you?" He was very astonished, and he said, "Tell your husband that I admire him very much…." He was very amazed; his admiration was for my husband. (Interviewee K)*

This excerpt captures how a married mother of two children displays the societal perceptions about intimacy and marriage, pregnancy and childbirth, and motherhood for women with disabilities.

In this article we concentrate on three major themes: intimacy and marriage, pregnancy and childbirth, and motherhood. The themes are explored based on their association with and contradiction of society's perception, and they are illustrated by selecting expressive excerpts from the interviews with employed disabled mothers of Addis Ababa, Ethiopia. The first part of the presentation of the analysis deals with the intimacy and marriage experiences of the disabled women. The second part of the presentation of the analysis covers the experiences of pregnancy and childbirth of the disabled mothers. The last part of the presentation of the analysis looks at the motherhood experiences of disabled mothers, with four sub-themes: motherhood feelings, mother-child relationship, motherhood responsibilities, and social support and perception.

Intimacy and marriage

According to the interviewees, being involved in a relationship is very difficult for disabled women. If they are in a relationship by any chance, the relationship may not continue, as mentioned by the majority of the interviewees. Four major reasons were noted for separation from the fathers of their children. There are also some who stay in married life, which is discussed in the section on the experiences of the married disabled mothers. The four major reasons for being single disabled mothers include eschewal by non-disabled men, financial problems, interference by siblings, and refraining by the disabled woman herself.

Avoidance of men: From the interview results, a clear notion emerged that the interviewees consider that non-disabled men do not want to involve themselves in a relationship with a disabled woman even if they are attracted to her. This concept is shown clearly in the following excerpt:

> *There was one visually impaired, very attractive girl. She always dressed well and kept herself looking nice. Once she was in a taxi wearing eyeglasses and there was a man next to her. He wanted to introduce himself to her and they exchanged telephone numbers. Finally, she reached her destination. While she was going out of the taxi, he realized that she was blind, and he said to her "Sorry! I don't want your number; do not try to call me." (Interviewee G)*

The quotation explains, on the one hand, the interest of the disabled woman in having a romantic relationship, and on the other hand, the avoidance of the man from getting involved in a romantic relationship with the disabled woman. It also implies the difficulty of intimacy and relationships with non-disabled men for disabled women.

Financial problems: On the other hand, the disabled women may establish a romantic relationship, but then the relationship may not continue due to different reasons. Interviewee I explained this issue as follows:

> *[I]t was very difficult to convince my boyfriend about the issue because he was not interested in having a baby at that time due to our financial condition, which was [insufficient] to cover the expenses of a new child. But I was looking*

> *forward to have my baby. In fact, he asked me to get an abortion but I said no to him. As a spiritual person, nothing comes to you without God's will. It was what I was seeking for years…. I was longing to be a mother, to have my own baby. As a result of my refusal, we got separated.*

In the above situation, the relationship could not continue because of pregnancy. The boyfriend gave her an ultimatum to choose either the relationship or the child. The reason for asking for an abortion was the financial inability to support the coming child, which resulted in their separation.

Interference of Siblings: Another reason for separation, stated by another interviewee, is the interference of siblings on both sides:

> *No, we did not continue to marriage. It was my own brother who tore us apart and separated us, and that was it…. There were no such things on his side. He even wanted to introduce me to his family. He wanted to marry and live with me…. There are also those in his family who think like my family, but he was not like that. I used to belittle myself, but he did not do that. (Interviewee E)*

The interviewee here implies that the relationship was discontinued because of the intervention of the family. In Ethiopian culture, family life is extended (Groce et al., 2013; Hogan, Berhanu, & Hailemariam, 1999), and major decisions in life like marriage are mostly decided not only by the couple but also by the family members. When it comes to disabled women, such a culture is typically more severe. The reason for family involvement is mostly either protection or stigmatization, as was mentioned by the interviewees. That is, the family may become the major decision maker on the marriage decision of their disabled daughter. They usually forbid their daughter with a disability from marriage for the reason of fear that she may be mistreated by a husband. Also, the family may share the belief of the society that disability prevents their daughter with a disability from handling the required responsibilities of a wife, in Ethiopian context such as handling house chores.

Avoidance of disabled women: The following excerpt entails the discontinuation of a relationship due to the decision of the disabled woman. Interviewee L mentioned her motivation to separate from her boyfriend as:

> *I had a boyfriend; actually, in our country it is not a simple matter for a physically disabled young female to have a boyfriend. There are a lot of*

> *problems. People shun you in a manner that is clearly observable or secretly based on reasons when you enter in such kind of relationships. ... I did not think about marriage; it was not in my dreams. I knew that it was possible but what I thought of first was the things which could obstruct it, so I did not give much thought to marriage. But when I say marriage, it is not only about the person who you marry; it is also the community that is there because of the relationship and being able to withstand the battle. This is, by the way, what I used to say at the time. I saw it as an unnecessary war; I saw it as an unnecessary sacrifice. So I blocked myself from getting into that situation, or I can say that I closed the opportunities that were leading to that because of fearing the results that would come afterwards, so as not to get hurt and make the sacrifice.*

In this quotation the interviewee describes the case of separation from a boyfriend because of the disabled woman's choice. It tells how the fear of making an unnecessary sacrifice leads her to bring the relationship to an end. She reveals that the trepidation was related both to the person that she would marry and to society's denial.

Marriage life: The second part of intimacy and marriage discusses the interviewees who are in married life. Married life for Ethiopian women is indispensable as within Ethiopian society people are likely to see a single woman as less fortunate, less respected and less valued. Thus, families often push their daughters to marry as soon as possible. However, for women with disabilities people in Ethiopian society expect the reverse and may react with disbelief if women with disability get married.

One interviewee who is married to a man with a disability stated:

> *... all the burdens are on me. Since he is unemployed at this moment, all the burdens are on me. In addition to that, he is not willing to help me at least by taking her [their daughter] to school. It is not difficult to take her to school because the school is not far from our house. As I have to prepare her lunch and make her ready, he should have at least taken her to school. Anyway, I am the one who takes my daughter to school, and after that I have to run to my office. (Interviewee A)*

The interviewee here does not consider her husband as a helpful person, while another interviewee who married a non-disabled person is very happy with her husband's behavior:

> *Generally, if you are a physically disabled person there are many sacrifices you should make. But, as a matter of chance I have never faced all these difficulties in relation with my husband, his family members... all of them are still good to me. (Interviewee G)*

The above two excerpts indicate the possibility of good married life with a non-disabled man and the likelihood of a less supportive married life by marrying a disabled man. Another interviewee mentioned that she divorced because of the behavioral change of her husband after having three kids:

> *Gradually he started showing a new character that he did not have before. He backslid from faith, he became a drunk, and it was very, very difficult for me to live with him. I tried to help him to restore his faith, but he was not willing to accept my advice; instead, he refused to accept it. Finally, I took the issue to court to get my divorce paper so as to keep my children with me to save them from his bad behavior. Finally, I got divorced and our relationship ended there. (Interviewee F)*

The interviewee further explains that all the responsibilities of raising the three children are left to her, and she also mentions that she enjoys taking care of the children.

Generally, intimacy and married life are mostly difficult, as mentioned by most of the interviewees. Most of the difficulties are intertwined with negative attitudes toward disabled people. Most relationships did not last for long. Next to the romantic relationship, the significant theme identified was the pregnancy experiences of the interviewed disabled women.

Pregnancy and giving birth

The Ethiopian custom forbids having sex and children outside marriage; it is a taboo. This taboo is recognized for women with disabilities, as people cannot believe that men want intimacy and marry women with disabilities. Yet, most of the mothers we interviewed were single mothers. The interview results show that all the single mothers got pregnant unintentionally, yet all of them were happy after having children. One of the single mothers got pregnant twice as a consequence of rapes by different men from her neighborhood as she was staying in the house alone. Subsequently, this section discusses the attitudes and behaviors of physicians towards the pregnancy of disabled women and the accessibility of health centers for pregnant disabled women. From the seven interviewed single mothers, all but two of the fathers were denying their fatherhood and were not providing support at all. The other six interviewees got pregnant within marriage.

Undesired pregnancy: the time of pregnancy of the interviewees was difficult for different reasons. Some were hiding their pregnancies as the following excerpt illustrates:

> *During pregnancy I did not go out for the whole nine months. When I was having the second baby I was even afraid to see people, as they were saying, "How could she make the same mistake knowingly," but I was raped for the second time. (Interviewee D)*

The above excerpt shows that the interviewee faced unwanted pregnancy and at the same time she was condemned by society. Rather than concentrating on the rape case it appears that society criticizes the disabled woman who was the victim. This made the time of pregnancy more difficult, since the interviewee stayed in her house for the whole nine months of her pregnancy. Another interviewee also revealed that she was hiding herself from people, including her family, until they started noticing her pregnancy:

> *I used to hide myself from my friends up until eight months. I even used to hide myself from my family members until they recognized it. After they learned it they accepted my pregnancy. They were saying, "Let her give birth because she is disabled; she will give birth to one who will lead her; her baby will have some benefit to her life." (Interviewee C)*

The following quotation illustrate societal condemnation makes the pregnancy more uncomfortable in addition to the inconvenience of the disability:

> *A pregnant physically disabled person is seen as something weird. It is something outside the box, which they have not seen before. They think that "She is walking with a crutch or she cannot walk on her legs well, but she is pregnant." Other times also they see you as a different being, and when you are pregnant it increases when they see you physically. Even at other times, all people are eying you.* (Interviewee M)

Apart from physical difficulties related to pregnancy the following quotation shows that women worry about anticipated difficulties after pregnancy. Interviewee J explains her worries:

> *Yes, being pregnant is very difficult for a disabled woman. It is very difficult, not comfortable. I have fallen down three times while I was pregnant; I used to worry, "Would my child turn out like me… maybe his hands or legs?" I couldn't sleep at the times I fell down. (Interviewee J)*

Here, the quotation explains that the disability makes the pregnancy time more hazardous. Thus, until the child is born and seen, the disabled woman cannot be certain about having a healthy infant.

Health and reproductive care: health care and health care education are often not supportive for disabled women. First of all, sexual education often is absent as the following quotation illustrates:

> *Once, I was expecting my menstruation to come but it did not come. I expected for a longer period of time and finally I learned that I was pregnant…. If I knew how to protect myself I would not have got pregnant. But after I knew my condition, I decided to give birth instead of going for abortion. I became a mother without marriage. (Interviewee B)*

Teaching disabled women about contraceptives is the responsibility of the professionals in the health centers, as it is not customary to discuss these issues with parents in Ethiopia (Taffa, Haimanot, Desalegn, Tesfaye, & Mohammed, 2017). Generally, in Ethiopia sexual reproductive health is given in schools. But, school girls are more influenced by their peers than their teachers (Yesus & Fantahun, 2010). Moreover, in Ethiopia not all children go to school, which is especially the case concerning children with disabilities in rural areas (Croft, 2013) and thus the regional health center is the best option to reach out for these girls. Yet, the majority of the interviewees are not satisfied with the services received from the health centers of Addis Ababa. The following excerpt from an interview with a disabled mother helps to clarify this:

> *Others can read and understand something about birth control. But it is not for us…. You must have a third party. It would be good if there were voice equipment or Braille reading in all health centers. Having such aids helps disabled people to get the service without any difficulties. Not only are that, but the roads to the health center other challenges. But it is good to have other aids that assist this group of people. The health center workers need to have sufficient knowledge about us. In addition to this, there is a need for an information desk that could assist the disabled groups. The disabled group needs to have adequate information like written materials and audio cassettes about birth control, and about health and other health-related issues. (Interviewee B)*

This quotation explains the awareness level of medical personnel and the need for special treatment for disabled women. According to the interview result, some doctors are not willing to serve disabled pregnant women properly:

> *I faced many difficulties from the hospital workers. They were not even willing to give me a medical card. After I learned about their refusal to accept me, I*

> *went to the previous hospital and reported everything to the doctor. Then he wrote them a letter and said to me, "If they refuse to accept you again, call me back and I will take the issue to the court." Having that letter I went to that medical center for medical treatment, but I did not get that particular person; instead, I got a woman. I informed her of everything that that man did to me, and she gave me a medical card. After that I went to that same doctor who refused to accept me. He did to me the same thing; he did not ask me anything but was asking my assistant about my health condition. (Interviewee A)*

Not only it was very difficult for this pregnant woman to get a medical card, she was also ignored as a person as the doctor avoided direct contact with her. All of the interviewees agreed that doctors in Ethiopia are untrained and unaware about disabilities and some training in that sense is needed.

Moreover, as illustrated below, doctors may condemn women for being pregnant:

> *Once I went to hospital for delivery, and there I found a doctor and he took me for delivery. And there I found a doctor and he told me that I made a wrong decision in becoming pregnant. (Interviewee F)*

This kind of advice from doctors is the experience of most of the interviewees, and the interviewees suggest that even if the doctors want to give some advice related to the pregnancy, the physicians should not say it during delivery. The other physician was generalizing all disabled women in the country, where there are a limited number of disabled mothers:

> *When I went to the hospital, as I told you, it was difficult; they do not have much support. They say, "All these disabled people are in a hurry to give birth. What is it?" ... Yes, they got angry in the hospital. Even when it was said, "Oh, please let her get in, she's sick" and the like, we were told, "What is it? Wait."... The baby was big, as I told you; he was not moving, and it was beyond my capability. When the person who took me to the hospital told the doctor that I was having great difficulty, he said, "Let her in," and I got in. I was then examined, and it was said that the labor will be seen after three minutes, but it was not.... [I then] delivered my baby [by Cesarean]. When a disabled mother goes to the hospital there is no one who quickly takes her to find a solution. (Interviewee H)*

As they were not approving the pregnancy of the disabled women, the interviewee had to suffer while waiting till she received proper treatment. Another interviewee finds that the attitudes of people working in the health centers may even lead to medical errors or mischief by doctors:

> *To be honest with you, I myself used to fear to go to hospital due to the occurrences of medical error. They may be reluctant to help a disabled mother and cause her to die. There are many challenges for disabled people.... There*

> *are times when doctors cut out the womb of a disabled mother without her willingness. (Interviewee I)*

This excerpt explains the extent of the physician's egotism – to cut out the womb of the disabled mother – and how the disabled mother was powerless.

Generally, all of the interviewees agree that the awareness level of the medical caregivers and doctors should be changed. Accessibility is also a major difficulty for pregnant disabled women, like the hospital buildings, beds, chairs, and information desks. Foremost, most interviewees were confronted with ignorance or even rejection by the physicians. The battle of the disabled women does not stop here; it continues after they become mothers, although the joy that they get from their motherhood experience reduces their grief

Motherhood

From the interviews four major sub-themes emerged under motherhood: motherhood feelings, mother-child relationship, motherhood responsibility, and social support and perception. These four sub-themes are presented using the interview results as they were told by the disabled mothers.

Motherhood feelings: All the interviewees expressed their feelings of motherhood with a good spirit. They consider their motherhood as a source of joy. For example, when Interviewee E was asked about her feeling of motherhood, her eyes became full of tears and she said, "I am very happy that I am a mother. I am very happy that I have a child. I am very happy, thanks to God…." Another interviewee articulated her feeling of motherhood as:

> *It's my children who are responsible for how I go through my day-to-day life. I have these views because they have made it possible for me to love myself, love my life, and become happy. My children are good to me and I can explain their goodness in that they love me. They truly love me a lot, and I can always see this. They understand me. Well, talking about the youngest one understanding physical disability now may not make sense, but my oldest child is now 12 years old. He knows my strength and my weakness. He can understand very well the situation I am in. He knows what physical disability is, and he is proud of me. So I am happy about this; he knows where I need support in the house, and he knows why I need it. He knows how I am different from other people and how I am better than others. This is a big blessing for me; this is a big gift. (Interviewee L)*

This excerpt shows that motherhood enabled the disabled woman to love herself and guide her life carefully. The understanding she gets from her children helped her look into herself and find new meanings and directions to her life. She also describes her experiences of motherhood feelings, beyond the caring and loving nature we expect a mother would have for her children. She is able to accept herself and her disability and to love herself through the love and acceptance she gets from her children. Another interviewee relates motherhood with the feelings of different stages of child development:

> *Motherhood starts from pregnancy time until your baby grows up. I still remember how I was doing the breastfeeding. It was a very good time. I still remember how my baby used to cry, how he was babbling and crying. All these things have something to do with your motherhood. (Interviewee I)*

The motherhood feeling of the interviewees is very positive; while talking about motherhood their faces seem to lighten-up almost as if forgetting the challenges that we were just discussing.

Mother-child relationship: A second theme that emerged from the interviews was the importance of the mother-child relationship. All of the interviewees emphasized having good and harmonious relationships with their children. Interviewee C explained her good relationship against a background of societal expectations on the contrary:

> *They (society) do not think that with disabled mothers that child-mother relationship exists. They do not think that children are important for disabled women. But for me as I knew that I could be a good mom and knew well my potential, motherhood is something very good and important, and it is a nice experience. We are very close. Based on [my daughter's] understanding level/ age level, I always tell her what is good and what is bad. She is very responsive.*

As captured in the interviewees, the mother-child relationship often goes beyond mother-child attachment. Interviewee F explained her relationship with her children as follows:

> *I always talk with my children in a very open manner…. I always tell them what is good and what is bad. And often I ask them what makes them happy and what makes them feel sorry. Most of the times I ask them to report to me their daily experiences. And they are always reporting what they have faced in their activities. Especially my elder daughter always reports to me anything she encountered in her daily life. We have a very close relationship. She is like both my close friend and my daughter.*

In addition to the joy of being a mother, it also shows that the relationship with their children is reciprocal. Women with disabilities have respectful relationships. Their children and husbands challenge the common opinion that stigmatize disability. At the same time the mother-child relation is different, as because of the dependency of the mother, the mother-child relationship may be more reciprocal than would the mother have been able. Interviewee J presents her relationship with her child as:

> *He is my brother, my son, and "my everything." He feels very sorry for me now. He gets up early in the morning, mops the house, prepares the bed, and boils tea. Now I have started learning at night, so he says to me, "You learn now as you have educated me; I can now tutor you." He truly does as much as he can; he sets up the things required for the coffee ceremony ... on his own, he prepares wott (Ethiopian traditional sauce) by chopping onions. [A]t this age he [helps] me [by] preparing these, and he consoles me. So I cannot explain the feeling of having a child; it makes you very happy.*

The 14-year old child is the mother's everything, as expressed by the interviewee.

Few interviewees stated that they can handle the motherhood responsibilities by themselves or without any support from others. But from the interview results, we could detect that they got help in one way or another. The above excerpt can be an example of a need for support from their underage children. The following comment also confirms the need for support:

> *When I was fetching water these days because there was a water cut, he takes it from me and puts it inside the house, saying, "Stop, you will have pain on your legs," and thinking about me. He has this understanding. (Interviewee E)*

Most interviewees indirectly showed that they get some support from their children, although the intention to have kids is not to get support. Thus, we can say that the children of the disabled women support their mothers either willingly or out of consideration for the need for support of their mothers. In Ethiopia, mothers getting support from children is customary but when it comes to disabled women, people relate the support of the children to the disability of the mothers.

Motherhood responsibilities**:** Most of the interviewees accepted that motherhood responsibility is very difficult unless they get support from another person, especially until the children start walking by themselves.

> *It is difficult to pick them up and down; I need someone's help. I cannot do it. I cannot move them around. My families help me with this kind of things at home. Otherwise, I cannot do it. (Interviewee D)*

This shows that the motherhood responsibility of disabled women requires support from other non-disabled persons. Another interviewee relates the motherhood responsibility with the perception of society as follows:

> *When my children get sick, even if my sister who is with me or the father of my children are there, if I don't face a problem which I cannot get out of I always go [to the doctor with them]. ..[…].. people felt that my presence there was unnecessary and they made comments. What these show me is that when people see this they just think that physically disabled women are unable to give birth to a child. If they think that it's possible they would ask whose child he is. My children are always thought to be my sister's children. It doesn't stop there; they say, "Why is it necessary for her to come?" Even when you tell them that they are my children, they ask, "Then why did she come?" Physical disability doesn't stop a mother from giving her child the necessary things. At least there is the psychological want to be with your child when he is sick, not to be apart, to take care of him yourself, you yourself wanting to hear what the doctor says and explaining the conditions that were there. (Interviewee L)*

From this excerpt we can see society's denial of the opportunity to look after the health of a child. When it comes to the disabled mother's experience, society denies her existence around the sick child. The excerpt also shows how society ignores the psychological needs of the disabled mother.

Social support and perception: although women face societal condemnation for becoming mothers, at the same time these children are seen as a resource to the disabled mothers. Indeed, as we have shown above, children are important for providing practical and emotional support. Yet again, the interviewees indicate that they often face derogatory remarks suggesting that the support is the reason to have children. In Interviewee A's words: "Society is happy when we give birth but they say, 'She gave birth to guide her or help her.' They do not focus on our motherhood." Interviewee B reveals the same idea in a different way:

> *For example, nobody says "your child" but they say "your eyes" or "your guide." I did not give birth to my child to show me a way; I gave birth to my child because I had to. For example, I do not take my daughter to place she does not want to go. She can join me only if she wants to go with me. I am not forcing her to lead me the way; it is not my intention. But people attached it with the idea of guiding me.*

Another interviewee emphasized the same idea by saying:

> *But when your family members such as your aunts, brother, sister… have negative attitudes towards you, it can affect your emotions. They cannot see my motherhood as they see the motherhood of others. They think as if I get someone who can assist my blindness. They do not think that I need a child like other mothers do. (Interviewee C)*

As mentioned by the interviewees, society does not think that disabled women can care, love, and do other things that mothers do for their children. The interviewees noted that there are groups of society who consider the motherhood of disabled women as creating problems for both the mothers and children. According to Interviewee I, there are also people who tell the disabled women that they do not have to give birth:

> *I remember on the fourth day after I gave birth I had to go to the hospital…. I was not able to climb into the car, and the driver was worried a lot. Finally, they put some stone so that I could climb up in the car. I remember he said to me, "You don't have to try to give birth again; you should stop it here." … People who are very close to me used to tell me that they may not take such responsibility if they were me. They say that they may adopt their nephew. We have many sacrifices that we are making as mothers. But it gets doubled when it comes to disabled mothers.*

This excerpt demonstrates a person's determination to advise the disabled mother not to have more children due to the challenge he observed. The same interviewee indicated two attitudes of society towards motherhood:

> *There are two types of people: The first group is those who disregard your motherhood, and the other group is those who appreciate your motherhood. There are times when your kids are considered as someone else's kids because people don't believe that you are capable of motherhood. At the same time there are groups who appreciate your motherhood, as they see the sacrifice you are making to raise your kids as the other mothers do…. If there is some stumbling block around me, I will take it out from my way and keep going…. You have to pay every necessary price for what you brought to this earth. (Interviewee I)*

This quotation shows the determination that the interviewee has to fulfill her motherhood responsibilities regardless of the good and bad influences of society. The perception of society is further discussed as follows:

> *She is a very well-known person. She is an artist, and we got along well since we had the media in common. She said, "Congratulations on your new baby; what did you have?" I said I had a baby boy. She asked, "Is the child also like you?" They think that if you are a physically disabled person, the child being*

> *born will also be a disabled one. When you get married also they think that your partner is also a physically disabled person. They ask, "Is your husband also like you?" I thought how they see it. We are in a community that concludes that a visually impaired person will have a visually impaired kid. Living in this community is difficult. I do not say it is easy. The main thing is the strength of the physically disabled mother. Otherwise, it is not easy. It depends on the way you respond to it. (Interviewee K)*

This quotation explains the awareness level of society about physical disability, motherhood by disabled women, and their relationships. Another interviewee mentioned about the family's disobeying the motherhood rights of disabled mothers:

> *But while the birth mother is there, the child may be told that her sister who didn't give birth to him is his mother, and he might not have the correct name of his father. Parents may do this because of not accepting the physical disability, and they might think that they are protecting the child and taking care of the child by doing so. But this deprives the mother of the grace of motherhood – her right. And the child may know about it later on, and when he does it is going to be something which will hurt him…. Even if she is a physically disabled mother in a difficult situation, she should be helped so that she can enjoy her motherhood experience. And the children should also know about it and live in this condition so that it is not difficult for them. (Interviewee L)*

This excerpt shows the scope of family interference to the extent of refusing to acknowledge the disabled woman as the child's mother and telling the child that some relative is his or her mother. This type of social influence excludes the disabled mother from the grace of motherhood (as stated by the interviewee) and also creates a negative effect on the child when he or she identifies the real mother with a disability.

In sum, motherhood experiences for the disabled women in general were gratifying for the women. It enabled to give *and* receive love, trust, respect and also responsibilities and social support. Motherhood for all of the respondents, despite adding challenges to their daily life, has empowered the women and gave them grace.

Discussion

This article focused on the life experiences of disabled mothers in Ethiopia. The major themes selected were the challenges of the disabled women in intimacy and their married lives, their pregnancy and childbirth, and their motherhood experiences. Interviews with 13 employed disabled mothers from Addis Ababa, capital city of Ethiopia, were held.

Most of the interviewed mothers with disabilities have reported that society doubts their ability to be intimate, become a wife and mother. Here we reflect on our empirical data with three complementary but not mutually exclusive theoretical frameworks: the Capability approach (Sen 1993), the (Family) Quality of Life approach (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006) and the Disability culture perspective (Peters, 2000).

We found significant to discuss the personal accounts of the interviewed women in a wider conceptual perspective. Moreover, reflecting on our material from the capability approach, the (family) quality of life approach and the disability culture perspectives gives practical potential and thus may offer opportunities to improve the lives of mothers with disabilities.

1. Capability approach

The capability approach (CA) is an ethical framework that states that social justice should focus on supporting the capabilities of individuals to conceive, pursue, and revise their life plans. (Alkire, 2002, 2005; Nussbaum, 2006; Robeyns, 2005; Sen, 1999; Vizard, 2006). The CA was developed by Sen (1980, 1993, 2009) with as a starting point two questions. One question is on the individual level: what is really important in people's lives for their welfare and wellbeing. The other question is on the societal level: suppose we want to determine how well a community manages to create a just society, how would we measure that? In the light of the first question the CA stresses the importance of values that people should achieve with and in their lives. Sen speaks of 'beings and doings people have reason to value'. In the light of the second question, people should be enabled and facilitated to realize these 'beings and doings'. This means that people should have the freedom to have the identities they choose (beings) and to do the things that add value for themselves and their environment (doings). Capabilities stand for a person's opportunity and ability to realize valuable outcomes, taking into account relevant personal characteristics and external factors: being able and enabled. In the CA it is recognized that all people are different in their resources and characteristics. Because people differ in their 'inputs' people also need different means or 'conversion factors' to achieve equity in opportunities and outcomes. So, justice is in the CA not considered as equality in means (everybody has the right of the same means) but as equity in outcomes (everybody should have the same opportunities to achieve valuable outcomes). Nevertheless, our data imply that the women with disabilities does not have equal opportunities.

According to Sen important values are group and context dependent and should not be formulated by experts but 'collected' in the target group in a democratic procedure. Values are ‘transformed to capabilities if they are important for a person in his/her life situation and if s/he is enabled and able to achieve the value in their live. Thus, the context is essential as our results show they mainly obtain what they do not value.

If we apply this framework to our empirical material we can consider the three emerging themes – intimacy, pregnancy and motherhood - as capabilities: they are valued high by the target group of disabled women. However, on the cultural and societal level these values of intimacy, pregnancy and motherhood are almost denied on the identity level to women with a disability. Obviously, for society the women in our interviews are ‘reduced’ to the single identity of being disabled, which leaves no room and is not compatible with the identities of being an intimate partner, being pregnant or being a mother. Partly as a consequence of this and partly as an independent factor also ‘doings’ are difficult to achieve. Achieving appropriate medical care for instance, is problematic because of the attitude of professionals (consequential to the identity issue), but also because of accessibility.

Notwithstanding these negative societal ‘conversion factors’, the women in the interviews show an admirable strength to overcome this opposition. They have already faced resistance in their lifespan and found ways through them. It can be argued that mothers with disabilities bring more personal resources and conversion factors to creating motherhood on their own terms than nondisabled women. They can do it again. They have already learned to survive with limited information and resources and they can use those skills for this new challenge.

Moreover, the study implies the need for the entitlements women with disabilities have on the society to achieve equity, i.e. the need to have more means to compensate for their disability. This is important as our results show they receive less means in practice.

2. Family quality of life approach

The findings of this study indicate interconnectedness between several life domains including family and social interactions, emotional, physical and material well-being. These life domains are conceptualized in (Family) Quality of life constructs that reflect a sensitizing approach to various challenges and provide a framework for understanding disability (Brown & Faragher, 2014). Quality of Life can be reflected as a model that recognizes what is important, necessary and satisfying in human way of life. Quality of Life can be understood as achieving goals in major life settings at a personal level and social well-being enjoyed by families and the wider community (Schippers & van Heumen, 2014). With the recognition of the family as an important resource for persons with disabilities, but at the same time the impact disability has on family life, Family quality of Life (FQoL) domains were formulated, including: family interactions, parenting, emotional wellbeing, physical and material wellbeing, influence of values and disability related support (Samuel, Rillotta, & Brown, 2012).

Overall, we can conclude from the findings in the Ethiopian context, that the FQoL domains that are related with the three themes of this study - parenthood and disability-related support- have impact at the majority of the interviewed disabled women. This is mainly due to the socially constructed believes – the domain of influence of values - that disabled women do not fulfill the requirements of being wives and mothers. On the one hand, the interview results showed that disabled women believe that being intimate, pregnant and mothers contribute to their quality of life. On the other hand, the influence of culture and believes of the society keep disabled women in their disadvantaged position.

The influence of values is eminent in this study. In Ethiopia, married life is perceived as the ultimate purpose in life for women. It is believed that satisfaction in married life will improve all other quality of life domains. Society will pity a woman if she is not married and does not have children. Moreover, although Ethiopian culture expects women to get married before giving birth, society has always disapproved disabled women marrying and having children. This is because in Ethiopia women are heavily involved in domestic labor although this is mostly unrecognized and undervalued. Despite of this fact domestic labor is recognized as substantial and important for the sustaining of the families and disabled women are not seen as capable in performing these tasks.

Thus, society is marginalizing disabled women by using negative attitudes and assuming an inadequacy of providing care and well-being for their children and/or family. Therefore, it is not surprising that married with and parented by women with disabilities are often seen as negative experiences instead of positive events. Despite the growing number of women in our society who have a disability this attitude still exists in developing countries such as Ethiopia. This indicates, in the context of the Ethiopian culture, that disabled women themselves, but also their families and the wider community in general will perceive their quality of life as low.

Furthermore, for most interviewed mothers with disabilities, their decision and ability to marriage and parenthood were not without challenges of their own. They face resistance not only on being intimate, but also after getting married and becoming pregnant. For instance, as expressed by most of the interviewees, in the medical centers there are no disability-related supports, which is another major FQoL domain: accessible, affordable, and appropriate health care.

Despite the absence of an infrastructure that supports physical and material well-being, and societal values that negatively influence the (family) quality of life, the resilience that disabled women have shown through their ability to give and receive loving relations with their children and their ability to raise children in relatively good health has empowered them to such an extent that they experience a much better quality of life since becoming mothers.

3. Disability culture perspective

Progressively, academics from the disability community call for using a disability-culture perspective (Kirsbbaum, 2000; Kuppers, 2011; Peters, 2000; Ripat & Woodgate, 2011), that is, recognizing disability as a socially constructed concept and pinpointing variables that encourage flexibility. This view shifts the emphasis from impairment to the stigma, prejudice, discrimination, marginalization, and disempowerment imposed on women with disabilities (Green, Davis, Karshmer, Marsh, & Straight, 2005; Van Brakel et al., 2012). In the Ethiopian context, the voice of people with disabilities is recently becoming much stronger, as is reflected in several grass-roots and self-advocacy movements. For example, the Ethiopian Women with Disabilities National Association (EWDNA) is a nonprofit organization based in Addis Ababa, founded in 2002 by seven women with disabilities and one professional volunteer. Our study can accelerate movements like these in showing that the disability experience brings a unique expertise to motherhood issues. Despite growing determinations to admit and support cultural experiences within most social structures, there is little awareness about disability culture among a wide array of society. This study reveals that disability and motherhood experiences contest customary stereotypes of incapable and helpless individuals, normalize the experience of having a disability, encourage independent functioning, and provide positive role models and disability-appropriate solutions. These cultural perspectives are especially important when considering mothers with disabilities who are exposed to general societal stigma and unjustified assumptions over their parenting capabilities. Finally, our data suggest that offering resources may facilitate women with disabilities in more fully enjoying intimacy, marriage and motherhood. Policies regarding family and social supports, such as accessibility, adapted services and communication, home modification and community access can strongly move the common family functioning and public involvement of mothers with disabilities and their families (Hu, Summers, Turnbull, & Zuna, 2011).

Strengths and Limitations of the study

This study is to our knowledge the first study on this topic of Ethiopian disabled women. Actually, choosing interviewees only from Addis Ababa limits the discussion in these regards. However, it is generally very difficult to get access to disabled women in the rural parts of Ethiopia, for instance because parents hide their disabled daughters fearing the prejudice of the society. Nonetheless, the fact that selecting interviewees who are employed and live in the city, Addis Ababa, showed the difficulty the employed disabled women of the city in realizing their motherhood. Moreover, from the challenges and difficulties experienced by relatively successful employed disabled women, we can only infer the immense extent of challenges and difficulties disabled women and/or mothers in rural parts of Ethiopia might face. The women in rural areas lack the independence that having (at least some) salary to support themselves with their kid/s. Furthermore, in Addis Ababa the society is relatively more aware about disability issues compared to the society who resides in the rural part of Ethiopia. Infrastructures such as: roads, houses, schools and hospitals are much better in Addis Ababa even though it is still extremely insufficient.

Another limitation of the study is that we asked the interviewees about their experiences as a ‘disabled’ mother. Adding the adjective ‘disabled’ may have elicited defensive reactions from the interviewees. Women were reluctant for instance to come up with possible negative effects of difficulties their children encountered. They emphasized their children’s strength, happiness and opportunities as a consequence of having a disabled mother. As this experience may certainly be one side of the coin, asking more openly about their experience as mothers may have also revealed possible difficulties.

Practical implications and Conclusion

Our study contributes to understanding the grace of motherhood of disabled women of the world. First and foremost, our interviewees find agency, resilience and pride in their experiences of intimacy, pregnancy and motherhood. This enables them to face physical and material challenges, negative societal expectations and hardships. By sharing their experiences women can empower and help each other. Also, transferring the communal family functioning and public participation in the lives of mothers with disabilities and their families require policies regarding family and social support. Adapting policies regarding individual, family and social supports, such as accessibility, adapted services and communication, home modification and community access, is highly needed in the Ethiopian context. In turn, they can positively impact the common functioning and public involvement of mothers with disabilities and their families.

Furthermore, our findings may help in communicating to the larger society to enhance the awareness people have about the love and competence disabled women have in intimacy and motherhood.

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Chapter five

The experiences of children with disabilities and primary caregivers on the social inclusion of children with disabilities in Ethiopia

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Abstract

This article presents the findings of a qualitative study on the social inclusion of children with disabilities in Addis Ababa, Ethiopia and how this affects their achievement of valued life goals. The thematic analysis is based on family quality of life and the capability approach, which are used to explain the effects of social inclusion (and exclusion) on children with disabilities and their families in three domains of quality of life (being, belonging and becoming). The study is based on focus group discussions with children with disabilities and primary caregivers of children with disabilities in Addis Ababa. The study also looked at how the social inclusion of children with disabilities can be actualised. The results of the study confirm the existence of considerable challenges to the social inclusion of children with disabilities in Addis Ababa, which is reflected in their capabilities The results suggest that children with disabilities need assistance and support to achieve a good quality of life. They also indicate the need for the involvement of the wider community to support children with disabilities and their families to enhance the capability of such children to improve their family quality of life.

Introduction

Social inclusion is an important element of well-being for children (Biggeri, Ballet & Comim, 2011). It is the process of improving the ability, opportunity, and dignity of people who are disadvantaged in terms of taking part in society on the basis of their identity (e.g., as disabled) (World Bank, 2013, p.4). Social inclusion is a key component of the UN *Convention on the Rights of Persons with Disabilities* (Hendricks, 2007) and, as a stated right, it is a legitimate goal for community-based services and support (Cobigo, Ouellette-Kuntz, Lysaght, & Martin, 2012).

People with disabilities, especially in low income countries, face many barriers to full participation in society and are, thus, likely to risk facing social exclusion (Islam, 2015) by family, friends, communities and the government. Their social networks are comprised mainly of family members and professionals (Steel, Poppe, Vandevelde, Van Hove, & Claes, 2011), although the latter are rare in developing countries (Samadi & McConkey, 2011). Children with disabilities and their family members experience bullying, stigmatisation and discrimination (Kinnear, Link, Ballan, & Fischbach, 2016). The intersection of disability and poverty aggravates their situations, making children with disabilities and their family members who live in poverty vulnerable and isolated (Trani, et al., 2015). As a result, children with disabilities experience high rates of social exclusion (Chamberlain, Kasari, & Rotheram-Fuller, 2007).

The presence of a child with a disability in a family also affects the lives of other family members (Valicenti-McDermott et al., 2015). Members of families with children who have disabilities, especially in developing countries such as Ethiopia, are at risk of increased stress, social isolation and stigmatisation, as well as decreased quality of life and psychological well-being (Gupta & Singhal, 2005).

Furthermore, children with disabilities need support and guidance from their families into adulthood (Aldersey, Francis, Haines, & Chiu, 2017). This draws attention to the ongoing need to support parents and primary caregivers across the lifespan (Bayat, 2007; Singer, Ethridge, & Aldana, 2007).

One way to address these isseus is to integrate the family quality of life and the capability approaches. Since disability impacts the whole family (Summers et al., 2005), reconnoitring the lives of children with disabilities and their family members, and constructing a contextual family quality of life based on the values and culture of the society in which they live (Shogren & Turnbull, 2006), is crucial to enable children with disabilities to enjoy the 'beings' and 'doings' that they value (Sen, 1992).

Although there are indications that social inclusion is a problem (Simplican, Leader, Kosciulek, & Leahy, 2015), there is a dearth of up-to-date research and scientific literature on the nature and severity of the social exclusion of children with disabilities in developing countries such as Ethiopia. In fact, in contrast to the numerous studies on social inclusion generally in developed countries, research on the social inclusion experiences of children with disabilities in developing countries is scarce. The studies available mostly focus on the requirement of social inclusion for the fulfilment of the educational needs of children with disabilities. This study attempts to fill this gap by building on the findings of a preliminary study in Addis Ababa, Ethiopia to explore the beliefs, attitudes, behaviours and experiences of children with disabilities and their primary caregivers in relation to the social inclusion of children with disabilities. It also aims to investigate how social inclusion tends to bring positive life changes to both disabled children and their families.

The specific research questions addressed were: 1) How do children with disabilities experience social inclusion? and 2) What are the primary caregivers' beliefs, attitudes and behaviours in relation to the social inclusion of their children with disabilities (Aldersey et al., 2017).

Method

Conceptual framework

Social inclusion was conceptualised for the purposes of this study using the theory of family quality of life and the capability approach. This is because social inclusion contributes to family quality of life (Schalock, 2004; Verdugo, Schalock, Keith, & Stancliffe, 2005) and gives children with disabilities opportunities to be involved in valued life domains (Sen, 1992). The investigation is based on the domains of quality of life identified by Raphael, Renwick et al. (1996) which can also work to family quality of life. The two theories capability approach and family quality of life are explained using the three domains, being, becoming and belonging, as they have social contexts that are important to the quality of life of children with disabilities and their family members (Brown, Cobigo, & Taylor, 2015). In this study we refer to the three domains as: 'being' (which is about who one is), 'belonging' (which involves the environment in which one fits), and 'becoming' (which refers to the purposeful 'doings' carried out by a person to express him/herself and to achieve personal goals, hopes and aspirations) (Zekovic & Renwick, 2003).

The capability approach, developed by Nobel prize laureate Amartya Sen, is an ethical framework that states that social justice should focus on supporting the capabilities of all individuals to conceive, pursue, and achieve their life plans (Sen, 1999; Venkatapuram, 2011). Capabilities are understood as the opportunity to fulfil 'functionings' or "beings and doings people have reason to value" (Sen, 1992) and that are feasible for a person to achieve. The capability approach looks at what is valuable to, and valued by, people and how they can achieve these in their life. The approach states explicitly that it is the shared responsibility of the individual and the social context to build up and facilitate a person's capability set so that they can be enabled to achieve a valuable life. This puts a claim on society, which is in line with the claims of the World Bank (2013) and Cobigo et al. (2012).

In the capability approach, resources or the 'means to achieve' a valuable life, such as income and wealth, but also health, only have meaning because of what individuals can 'be' and 'do' through using and 'converting' such means into outcomes. For Sen, equity in opportunities/capabilities (i.e., the 'freedom to achieve' the important goals that people have) is important, not equality in means, as in most economic and political philosophical theories. Thus, instead of focusing exclusively on the means or instrumental value of goods, the capability approach advocates for a focus on what we really value and care about and on what individuals are practically able and enabled to be and do, i.e., on what 'achievements' they can attain.

Moreover, the desire to be valued by the society, for example by peers, has traditionally been explained by the existence of natural instinct: social inclusion is considered a normal part of every person's identity. In addition, being socially isolated means limited access to external support (Chenoweth & Stehlik, 2004), which makes children with disabilities dependent only on their families, which in turn affects family quality of life. The domains of family quality of life used in this paper (being, belonging and becoming) of Raphael, Renwick et al. (1996) explain the effects of social inclusion (and exclusion) experiences on children with disabilities and their families. Based on the same authors, these three domains are further classified into sub-domains: (1) being with sub-domains of ‘physical being’, ‘psychological being’ and ‘spiritual being’, (2) belonging with sub-domains of ‘physical belonging’, ‘social belonging’ and ‘community belonging’, and (3) becoming with sub-domains of ‘growth becoming’, ‘practical becoming’ and ‘leisure becoming’.

The same domains of being, belonging and becoming can also be explained in terms of the capability model: being is similar to the ‘means to achieve’ in the capability approach; belonging is partly similar to ‘conversion factors’ and partly to ‘capabilities’ (‘freedom to achieve’); and becoming is similar to ‘functionings’ (‘achievements’). Thus, the three domains of family quality of life appear to fit nicely with the capability model.

Focus group participants and setting

The methodology used was focus group discussions with children with disabilities and primary caregivers of children with disabilities. The focus group discussions were conducted in the conference room of the School of Commerce, Addis Ababa University. A representative of the Ethiopian National Disability Action Network (ENDAN) was used to choose the participants. The representative met the children with disabilities and primary caregivers, who were put forward by different NGOs under the umbrella of ENDAN. The representative informed the children with disabilities and primary caregivers about the general objective of the study and the major theme of the focus group discussion. Those who agreed to participate were selected for the focus group discussion.

Nine children with disabilities participated in the first focus group discussion: eight of them were 12–17 years old, one was 18 years old, two were deaf (male), two had leg problems (female, one a wheel chair user), and five were blind (female). In the second focus group discussion, eight primary caregivers of children with disabilities participated (six were mothers, one was a blind woman who runs an NGO taking care of blind children, and one was an uncle of a child with a disability). The duration of the focus group discussion with children with disabilities was 1 hour and 48 minutes and with primary caregivers was 2 hours and 6 minutes. The result of the analysis of the two focus group discussions are presented together and the most expressive excerpts are used for all themes and sub-themes.

Procedures

A moderator (a blind woman) facilitated the focus group discussions and elaborated on what social inclusion means in the context of the study at the beginning of each session. There was also a sign language translator present for children with a hearing impairment. The first author controlled the voice recorders and took notes. A semi-structured interview guide was used to provide general direction for the focus group discussions.

Ethical review procedures

In order to ensure that ethical practices were followed and maintained throughout the research, various procedures and actions were taken to maintain the security and trust of the participants. For the focus group discussions, a letter of consent was signed by the NGO representative for each child participant and by each primary caregiver participant. Prior to signing, the focus group participants were advised that they could withdraw from the study at any time.

Permission to record the focus group discussions was sought as both a courtesy and for clarity of intent, as well as to reveal the nature of the study. For the ethical procedures, ethical approval was granted by the School of Social and Behavioural Sciences Ethics Review Board of Tilburg University.

Data analysis

A hybrid process of inductive and deductive thematic analysis was used (Fereday & Muir-Cochrane, 2006). The methodological approach integrated data-driven codes with theory-driven ones. First the interview questions were designed based on the theory of family quality of life and the capability approach, focusing on the social inclusion experiences of children with disabilities. Second, based on the manuscripts of the two focus group discussions themes were identified. Third, the identified themes from the manuscripts of the focus group discussions were reframed using the three domains: being, belonging and becoming (Raphael, Renwick et al., 1996).

The analysis process began with translating the voice recorded focus group discussions into manuscripts, followed by a repeated reading of the text data by all the authors. The next step was to identify specific text segments related to the objectives and coding (Thomas, 2006). Then the segments of text were labelled to create categories, resulting in less overlap and redundancy among the categories, which finally led to a model incorporating the most important categories (Attride-Stirling, 2001; Green et al., 2007). From these important categories, themes were identified (LaRossa, 2005). The identified categorised themes from the general coding were then re-categorised using the three domains identified by Raphael, Renwick et al. (1996) (Edmunds & Brown, 2012). This was followed by differentiating the excerpts using different colours for the three themes (Burnard, Gill, Stewart, Treasure, & Chadwick, 2008; Green et al., 2007). Next, the most expressive quotes were selected for presentation. Moreover, sub-themes for the three major themes, as identified by Raphael, Renwick et al. (1996), were used. Finally, the findings were analysed and interpreted in relation to the conceptual framework.

Results

The findings from the analysis of the three themes of coded data that emerged and were categorised under the quality of life domains (Raphael, Renwick, Brown, & Rootman, 1996). The analysis follows the interpretations given to being, belonging and becoming by Raphael, Renwick et al (1996). The same authors explain that these three domains are intertwined, which was also experienced in this study while categorising the excerpts under the three domains. In addition to the intertwined nature of the three domains, the focus group discussions resulted in overlaps between the domains due to the fact that the focus group discussions focused on social inclusion, and because of the complexity of the life experiences of the participant children with disabilities. For example, in the following excerpt the three major domains (being, becoming, and belonging) are all represented:

> *Since I cannot hear, I'm not able to talk most of the time, so I don't play that much with those who do hear. But I play just by looking. I mostly talk with those who have a hearing impairment. The others laugh at me when I talk so I don't want to talk to them. I want to spend the time in silence. I play with my father and mother a little. Other than that, there is nothing else that I do.* (Child 8)

The first statements (*"Since I cannot hear, I'm not able to talk most of the time so I don't play that much with those who do hear. But I play just by looking. I mostly talk with those who have a hearing impairment.*") relate to both being and becoming, while the subsequent statements ("*The others laugh at me when I talk so I don't want to talk to them. I want to spend the time in silence. I play with my father and mother a little. Other than that there is nothing else that I do."*) relate to belonging and becoming.

With the statement *"Since I cannot hear"*, the child appears to identify with being deaf. By continuing with *"I am not able to talk most of the time so I don't play"*, the child relates his 'being' (hearing impaired) to the inability to 'become' (to take part in playing with children without a disability).

Being

Both groups of participants in the focus group discussions (children with disabilities and the primary caregivers of children with disabilities) described the theme of ‘being’ in relation to: the impact of having a disability, coping with it and being confronted with all the irrational beliefs around the disability. The participants agreed that the general physical condition/disability affects the social inclusion of children with disabilities. Some children participants indicated that their disability precludes them from being included in society:

> *I say that we are not much included in society. Because I have a hearing impairment, there is nothing much I can talk about with others in society. This is because when I talk using sign language they laugh at me. I cannot hear so I feel it very much.* (Child 7)

The above quote explains the impact that hearing impairment has on the social inclusion of the child. The participant explains that he cannot communicate with people who cannot use sign language and sometimes when he tries to communicate, people laugh at him. He also says that the impact of his disability affects his feelings.

Some impacts of disability can be due to irrational beliefs and fears about disability, as explained by a primary caregiver who is the mother of a blind child:

> *The doctor said that her pupil has been damaged and that this was hereditary. … it is God who passes it to us from above. We can’t buy and bring disease, it is hereditary ho ho... I also took her to another hospital, but they told me that nothing could be done as her pupil is damaged.* (Primary caregiver 4)

This irrational explanation of the cause of the child’s disability is given by an educated physician, indicating the low level of awareness about disability in Ethiopia.

Another primary caregiver explained how physicians often equate disability with inability to perform simple tasks:

> *Someone from here goes with them when they [disabled children] go to a hospital. There is a girl who is their assistant. As they are teenagers and young, there might be secrets they want to share with the doctor. But there are doctors who ask the assistant to come in the room and undress these girls. When this happens the girls feel bad and ask why it is necessary, as they can do it*

> *themselves. After they come back here, they laugh about how undressing is thought of as a difficult thing, but they feel it at the time. Being visually impaired doesn't stop you from being able to dress and undress yourself. The doctors are happy to talk with them when their assistant is present, but not when they are alone. These things hurt their morale in some way.* (Primary caregiver 3)

The above excerpt highlights some of the misguided beliefs of physicians about children with disabilities, such as blind children, who are often considered incapable of performing a simple task such us undressing, and the lack of understanding of their feelings.

The children explained that their disability is generally considered to be the result of a curse, which presents different challenges, as indicated in the following excerpt:

> *I lost my sight when my mother took traditional medicine, when she gave birth to me. They used to say this is a curse, it's because you are cursed. She just keeps quiet and doesn't say anything. When the people around the area meet me, the children think and do shrewd things. They insult me and knowingly lead me into a ditch.* (Child 2)

There are people who believe that the disabilities of children are contagious, as explained in the following excerpt:

> *People around my neighbourhood also say "go away we don't want to play with you". When someone holds my hand they say "don't hold her it will be transmitted to you". So they don't hold me.* (Child 3*)*

Another child explained that her disability is always considered to be an inability and people try to give her money, as most people in Ethiopia assume that children with disabilities are beggars, even if they are able to do many things:

> *The other thing I don't want to miss saying is that in areas outside the city, around rural areas, they think that we can't do anything, so wherever they see us they give us money without asking us. They see us as beggars. Thank God we can do work. So it would be good if they were educated – if education is given to the whole community*. (Child 1)

An excerpt from a mother of a disabled child in a focus group discussion confirms the widely held belief that children with disabilities cannot be educated: "There was someone who told me that it was impossible for my daughter to learn; I was very sad at that time. But I thank St. Gabriel, now I am very happy" (Primary caregiver 6).

Many primary caregivers shared similar stories regarding the judgments passed by society in relation to children with disabilities. For example, one primary caregiver described the difficulties experienced by children with disabilities when buying clothes:

> *When these children get money, they go to shopping centres. They tell me that the shopkeepers tell them that the item isn't suitable for them or they can't afford it. How can others know if they can't afford it by looking at them? The children relate this to their physical disability.* (Primary caregiver 3)

This again illustrates the illogical beliefs held by society in relation to the capability of children with disabilities.

The above excerpts reveal the social exclusion of children with disabilities and their families, due to misconceptions about disability. These misconceptions and related practices also affect the psychological well-being of children with disabilities. The following excerpt indicates the uneasiness felt by children with disabilities when others stare at them:

> *In addition, around the Amhara region when a blind or physically disabled person comes, they circle that person and stare. And that person will wonder why. They make them think what is wrong with me, do I have dirt on me?(Child 3*)

The misconceptions of society about disability also affect the psychological well-being of the family members of children with disabilities. For example, in the focus group discussion with primary caregivers a partially-blind mother who has a blind daughter described the emotions she feels when they are insulted because of their disability:

> *…they insult her saying that she is blind and her mother is also blind. Why doesn't the government find a solution for this, as we are the one's holding the problem? We are carrying our disability in our homes on our own, but why? Why do we get shunned in the place where we are born, the government should do something about this. Every person should have rights. Our rights should not be taken away from us (crying).* (Primary caregiver 4)

Belonging

The belonging describes the aspects of the physical, social and community environment that influence inclusion. In relation to physical belonging, most of the participants repeatedly mentioned belonging at school. One of the children in the focus group discussion pointed out that children with disabilities can do what others do in school, if they are equally included and have equal access:

> *I want us, the children with disabilities, to have equal rights. Because we don't have to convince ourselves that we can. But even if we can we need people to support us. The support we want is regarding Braille books and to help us copy by reading to us. We want to be equal. We want them to see us as equal. We don't want them to be repulsed by us. We can do anything. There is nothing missing from us. We have to try to do things first by ourselves. We have to believe that we can do it first.* (Child 2)

From this excerpt we can infer that children with disabilities in Addis Ababa are not included equally at school. They do not have equal access to educational resources such as Braille books and mentioned the need for such resources so that they can equally belong physically at school:

> *I am going to say something like she said. For the visually impaired we are usually challenged by books. I want books to be given to us equally. The other thing is roads, so that the roads are convenient.* (Child 5)

The other issue mentioned in the focus group discussion with children with disabilities in relation to physical belonging is difficulties in communication:

> *Mostly those who work at the Dil Betigil library have hearing impairment. And it is difficult for the visually impaired to communicate with them. Sometimes when I go to ask for a book it is very difficult for me. I should go and get it written… so it is good if some training is given. At least, even if we don't see the answer, so that they could accept our question and translate it. We don't see the answer, but just to ask our question.* (Child 2)

From this we can see the lack of inclusion of children with disabilities in school. It seems that schools in Addis Ababa do not recognise the presence and needs of blind students.

The accessibility of toilets in schools was another issue raised by participants in relation to physical belonging, as expressed by Child 9: "The toilet is not convenient. Since the kids also make it dirty, it is not convenient". The same child also mentioned that she does not drink whenever she has to go to school, as it is impossible for her to use the toilet in her school.

On the other hand, the primary caregivers who participated in the focus groups talked about housing issues, in relation to their physical belonging in the community. One primary caregiver shared the difficulty renting a house if one has a child with a disability:

> *It is difficult if you have a physically disabled child. I was looking to rent a house after getting out of my previous home. I made a down payment to the owner who was going to rent me the house, but she gave me back my money the next day just because I told her that I have a child with disability. She told me that her grandchildren come to the house for vacation and they might go through some thing if they see my daughter. So she gave me back my money. It is very painful to have a child with disability. There was a day when they insulted me, saying why don't I keep silent and just raise my child with a disability.* (Primary caregiver 7)

This indicates that the whole family can be socially excluded due to the presence of a child with a disability. The social belonging of children with disabilities was expressed by participants in different ways. It includes links with the social environment and a sense of acceptance by intimate others, family members, friends, the neighbourhood and the community.

Some children with disabilities expressed a secure sense of belonging to their families and neighbourhood:

> *There is no problem in the family. Kids from our neighbourhood also come so that I won't fall down. They come close to me so that I won't have to go far. And I play with them.* (Child 1)

However, others described their belonging to other family members as limited:

> *Regarding family, I say it's ok. It's in the middle. Sometimes I encounter things; for example, there is nothing on TV for the hearing impaired. My family watches TV and they laugh when there is something funny. But I don't have anything that I laugh at. So I feel left out. I usually don't spend much time in the house. I go home when it is very late. I stand at the door until it is 7:30 pm. This is because there is nothing I can play with at home.* (Child 7)

Another child explained that the belonging he has with his family members is traditional in the sense that they lack of knowledge about disability:

> *They don't know that much. They talk to me traditionally. For example, they may even call out at me like "you deaf kid". These things make me very angry. Since it is traditional and they don't have that much knowledge, they don't know sign language that much too. They only know common words like eat or drink.* (Child 8)

Another child in the focus group discussion explained that she does not feel any belonging in her family except with her mother:

> *In the family I am not included. They don't include me in anything. Since we live in a rural area, my father doesn't include me at all. Now, he has divorced my mother; he took all the children who are visually abled and gave me to my mother. He said "take your share and I have taken my share". She agreed and took me. She went through a lot of trouble and got me into a school around Oromia area. I learned there and came here. He doesn't allow my brothers and sisters to come and greet me. He tells them not to go to my house. He is not happy that I was born. He doesn't think I can do anything. He is amazed even how I move around from place to place*. (Child 3)

Most of the children with disabilities who participated in the focus group discussion explained that they feeling a greater sense of belonging with their mothers:

> *Most of the time I talk with my mother. She is the one I am close to. My mother tells me to buy bread. We speak in traditional language. But I don't talk with other people who are outside. For example if I go to the market and ask for bread, I may say something else. When he brings it and I say this is not what I want, the shopkeeper gets angry. So it is difficult for me to communicate.* (Child 7)

All of the primary caregivers said that they have a great sense of belonging with their children with disabilities. For example:

> *My children are comfortable around me and I am also comfortable around my children. I also have other children who can hear. They also love me and I also love them. We live together by understanding one another. They live by having good relations with the neighbours. They also have good relations within the family.* (Primary caregiver 2)

Primary caregiver 8 explained that her high level of belonging with her daughter isolated her from her other family members:

> *Her change is good. I was not ashamed of her even when she was very small. I used to carry her on my back from Merkato to Kera and take her to school. I am not ashamed of her. Family members used to tell me to give her away to organisations or to leave her. But I told them I wouldn't leave her and I would raise her even if I had to beg. We don't meet with our family because of her. They don't want to be close to me.* (Primary caregiver 8)

The other part of social belonging expressed by the participants relates to community belonging, which represents access to resources usually available to community members, such as social services. Regarding community belonging, the participants in the focus group discussions raised issues related to health services, roads and transportation.

Participants in the focus group discussions described problems with the design, construction and maintenance of footpaths, crossings, paved areas and streets for blind people and how these affect their mobility:

> *What I want to say is concerning roads. The area that I live in, Shiromeda, has narrow streets …. When we take the corner of the street, there are people there who lay out clothes to sell. As we touch their clothes they push us towards the cars saying go over there. If we go towards the cars they will hurt us, so it would be good if the road is adjusted and wider sidewalks and roadways made.* (Child 3)

While discussing social inclusion in relation to roads, a mother of a child who uses a wheelchair explained the need to accompany her child to school and back, even though the child believes that the road is good:

> *I am very happy since my daughter started school, but I am the one who takes her there. She worries and tells me that she can go on her own as the road is ok. But it is not safe. I tell her not to worry, as it is not difficult for me, even if they say it is hereditary.* (Primary caregiver 8)

Transportation was the other aspect of community belonging discussed in the focus group discussions. Without accessible transportation, children with disabilities are more likely to be excluded from services and social contact, as expressed in the following excerpt:

> *Those who have a hearing impairment have transportation problems. We see Mekanisa [street name] posted on the taxi and we get in, but the taxi is going in another direction. The postings should be correct, as they are posted to help us.*

> *We hear using our eyes. We talk using sign language. So what we hear with our eyes is what we see.* (Child 8)

The participants also believe that they are socially excluded in relation to access to health care centres. For example, a deaf child explained that the deaf cannot communicate with doctors in the health care centres, as there are no people who know sign language:

> *The second is on health centres. It would be good if they [health facility staff] are educated. If someone who has a disability is sick, how are they going to communicate? If he [the deaf person] comes and asks, they may give him another medicine. He may go because they [health facility staff] could not understand each other. It would be good if more people knew sign language or a translator was available.* (Child 7)

One of the primary caregivers explained the need for community belonging in relation to disability-related support as follows:

> *There are not enough wheel chairs or crutches. If there is a way that organisations for people with disabilities could produce these materials it would be good. A visually impaired child cannot go to school without a slate, styles and a cane. A physically disabled child can't go to school without a wheelchair. They have already described sign language in a good way. It is good if these kinds of things are wide spread. But the main thing that motivates parents and children, I am saying this because I think it will help your study, there is no social security in our country. There is something that started called Safety net, but I don't know to what extent it is in place.* (Primary caregiver 4)

Another primary caregiver suggested the need for government intervention:

> *The government is the main one. It should arrange these things. There is a lot of talk about disability, but not much practical work can be seen. We see there is good growth in our country for healthy people. The buildings and roads which are being built are very good, but even these don't take into consideration people with disabilities. We can see it starting from the hospitals, roads and buildings. Just like my sister stated earlier, how is it possible to live on the fourth floor with a child with a physical disability? The government should take action on these issues instead of talking about it. We are all talking about it.* (Primary caregiver 6)

Becoming

The becoming of the analysis covers growth becoming, practical becoming and leisure becoming. It describes the actual activities that can be carried out in school, at home and in relation to leisure. The majority of children with disabilities who participated in the focus group discussion described accomplishment in education as their major growth becoming. They said that this achievement contributes to changing society's beliefs about children with disabilities:

> *What is expected from us as children with disabilities is to be strong and get educated so that we can achieve our goals. Whenever we grow the community will start changing. In some places they only see adults with disabilities, they don't think about those who are children.* (Child 8)

Even though being educated is the primary 'becoming' valued by children with disabilities, participants in the focus group discussions mentioned different obstacles that they face in school. The first one is the inaccessibility of schools, including the unavailability of slates and styles for blind students, the inaccessibility of school buildings for students who use wheel chairs, no or limited teachers who speak sign language communication. These pose obstacles to children with disabilities achieving their full growth potential in relation to 'becoming' in education. This is explained in the following excerpt.

> *We are learning in school through a translator. But the translators are few. There should be more translators. In our school we have four translators, but we don't know how many periods they will teach. We have seven periods per day. It is better in our school than in other places, where they have only two translators. Firstly, they [the translators] are overworked and secondly we don't get information correctly. If translators are hired, it should be in bulk. Or all the teachers in school should know how to teach in sign language.* (Child 7)

In the focus group discussion with primary caregivers, a mother of a child with a disability stressed the need for government intervention to provide educational opportunities for all children:

> *I would be happy if the government intervenes and everybody gets an education. My child is very happy to learn with others. I can't speak the [sign] language, but I can understand and communicate with him because I am his mother. But his sister has learnt [sign language] and he communicates well with her. He communicates with those who know how to speak sign language, but not with other children in the neighbourhood. I would be happy if everyone could learn this form of communication. Then my son would be able to communicate freely everywhere he goes.* (Primary caregiver 1)

Practical becoming was the other important issue raised by the participants in the focus group discussion. The two main aspects of practical becoming expressed by the participants were handling domestic activities such as household chores and participating in school clubs. Child 4 explained that she handles some household chores, as her mother understands what disability means:

> *Since my mother is a little bit educated, I tell her to give me some chores. She says: I know you can do it, but you'll be tired. I tell her that I will do what I can and when I get tired I will leave it. I do some chores and she lets me; she doesn't say anything. She wouldn't even say anything if I went to the lake to bring water. But other people are amazed they say: "how can she tell her to do this, how can she move"… this amazes them.* (Child 4)

Child 2 also described handling some household chores: "I also do chores there. But they tell me not to. They say "you'll hurt your hand".

While the children who participated in the focus group discussion said that they know about the presence of clubs in schools, they said that they do not participate:

> *There are clubs. But as I have a communication problem, I don't participate. They have asked me a lot of times. But as I don't ask them the details, like what time it is, I don't participate.* (Child 8)

Child 3, who is blind, said that she does not participate in school clubs: "There is club, but I've only heard of those who can see participating. I've never seen those who have a visual impairment participate".

The other aspect of 'becoming' discussed as part of social inclusion was leisure becoming, which includes leisure-time activities that promote relaxation and reduce stress. These include short duration activities, such as neighbourhood walks, or family visits, or longer duration activities such as vacations or holidays.

Some of the children with disabilities revealed that they play at home, in the neighbourhood and at school: “They let me play both at home and at school. I play with everybody in my neighbourhood. I also play at school”. Some others said that they try to play even if it does not last for long: “I play with them, they first gather around then they leave me and go”.

Primary caregivers pointed out the need for playgrounds for children with disabilities. One mother explained that she wants to take her child to a playground, but is limited because the playgrounds available in Addis Ababa are not suitable:

> *If I want to take my child to play, she can’t play anywhere. It is not only my child, but all children with disabilities. Is there a playground which is suitable for the visually impaired? Is there a playground for children with a hearing impairment? Is there a playground for children who have disabilities on their arms and legs? But there are many playgrounds for the children without disabilities. Why doesn’t the government intervene here? Aren’t the physically disabled also citizens? Aren’t the physically disabled also born as children? There is nothing for children with disabilities.* (Primary caregiver 7)

Primary caregivers also explained the need for games and care centres for children with disabilities:

> *Let us talk about games and child care centres for our physically disabled children. Would they take them? There is no one. They wouldn’t consider it, I am telling you the truth. They are for the healthy ones, but they wouldn’t think anything for the physically disabled. So if these things are included, if my child had a place where she could play and if there was some place I could take her, I would be happy.* (Primary caregiver 8)

Discussion

This study aimed to explore the social inclusion of children with disabilities through the combined lens of quality of life and the capability approach. Data were gathered about social inclusion of children with disabilities with different disabilities using two focus group discussions.-The data from the focus group discussions were analysed using the three themes: being, belonging and becoming, which reflect the central line of ‘means to achieve’, ‘freedom to achieve’ and ‘achievements’ in the capability approach.

The results indicate that children with disabilities are often socially and societally excluded, although most reported that they have a high level of social inclusion within their families. In addition, the results indicate that the family members of children with disabilities also face social exclusion.

This study highlights the need of children with disabilities to be socially included as a capability as such, but also in order to achieve different capabilities or 'functionings', including leisure activities, communication, social activities, education, mobility (Trani, Bakhshi, Bellanca, Biggeri, & Marchetta, 2011). However, not all of these capabilities/aspects of social inclusion are available to children with disabilities. For example, the results of the focus group discussions highlight the reality of rejection for children with disabilities, who spoke of their experiences with bullying, exclusion and sometimes violence (e.g., like leading blind children to a ditch).

Children with disabilities are also excluded as being 'different' from other community members, as they do not perform certain functionings (Chenoweth, 2004). Children with disabilities reported that they do not participate in school clubs and organisations, seldom get together with peers outside the classroom, and are less involved in all school activities. This is because the environment hinders the participation of children with disabilities in school and the resources needed to support their participation are inadequate (Coster et al., 2013). However, society perceives that they are not participating in school activities because of their incapacity. Those who have had the opportunity to participate in education take pride in that and have formed own sub-groups with siblings or other people with impairments, which act as 'support groups' for them.

These results suggest that the opportunities/capabilities and functionings of children with disabilities in low income countries such as Ethiopia are limited. This, in turn, affects the quality of life of families of children with disabilities. Thus, in order to create social inclusion for children with disabilities, the whole family needs to be supported (Heiman, 2002). This stresses the need for supporting the whole family, which is also favorable for the social inclusion of the children (Heiman, 2002; Xu, 2007).

The participants in both focus group discussions voiced the need for empowerment. The results of the study indicate the strength of children with disabilities, because, despite all of these problems, they still believe that they can do everything, especially if they can get support. From the results, it is clear that supporting primary caregivers is important to empower children with disabilities and their family members. Primary caregivers of children with disabilities in developing countries such as Ethiopia experience the double challenge of meeting the financial and emotional needs of the entire family, as well as coping with the demands of caring for a child with special needs, with less opportunities for support from relatives, the community and the government than they might have if they were in a developed country (Divan, Vajaratkar, Desai, Strik-Lievers & Patel, 2012). The results of this study indicate that children with disabilities have a high level of motivation to participate socially, such as by learning, participating in social activities and playing. So, there are no barriers for social inclusion on the part of the children themselves. These strengths of children with disabilities can be used in structuring supporting family-centred services.

The focus group discussions also brought forward that fathers are often not willing to (financially) support their children, which lowers the financial means and hence the quality of life of the family.

Lack of support services can make children with disabilities overly dependent on family members (Wang & Brown, 2009) and can prevent both children with disabilities and their family members from being economically active and socially included.

Limitations and strengths of the study

Even though the study covered many areas of social inclusion of children with disabilities and their primary caregivers, it would have been more comprehensive if the focus group discussions were not limited to participants under the umbrella of one NGO. The strength of this study is that it fills a gap in information about social inclusion and family quality of life issues of children in low and middle income countries, particularly since the study incorporates both the views of children and their primary caregivers.

Conclusion

Quality of life for families with children with disabilities, in terms of achieving capabilities and valuable functionings, has emerged as a useful indicator of the implementation of policies regarding disabilities. Primary caregivers of children with disabilities sometimes need support so that they can raise their children at home and fully participate in community life. Consequently, considering the involvement of primary caregivers of children with disabilities and determining what factors influence the well-being of children with disabilities is indispensable for the improvement of interventions, facilities, services and support; this is an area of analysis that requires further study.

Children with disabilities in Addis Ababa believe in themselves and their ability to achieve, if they have access to the means (e.g., resources such as Braille text books and services such as those of an interpreter). Thus, the opportunity and freedom to achieve important goals (capabilities), such as being educated, are the main factors of the social inclusion of children with disabilities.

Based on the results of this study, the following practical recommendations are made:

- Support children with disabilities and their family members by adopting a family-centred approach to service provision and by using family quality of life in terms of achieving capabilities as an indicator of the social inclusion of children with disabilities.
- Raise the awareness of children with disabilities so that they know themselves: their strengths, weaknesses, needs and preferences, and have the capability to decide what is important to them.

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Chapter 6

General Discussion

6.1 Introduction

> *I believe that the mentality of the people I have met during my work has changed for good, because the people near to me understand the things I have gone through and know that I can work. Therefore, I think that when these people meet people like me and other people with different kinds of disabilities they will be supportive. This is one of the things. The other thing is that physically disabled women like me have helped other physically disabled women to go out there. We have served as role models for them. And I think this is a positive thing. People have seen that we can learn. There may be other women whom you have met, and not met, while conducting this research. It is not only me, but other women with disabilities can learn from the ones who were there at this time. They will see that we can have a social life, meet people and understand each other, be friends, have a family, have children and raise them with love; that we can accept love and attend work. I think all these things have a positive influence. (Interview round 1, 2013, 43 years old woman using a wheelchair, a project coordinator with second degree in gender studies)*

The opportunities that people with disabilities have to exercise their capabilities in the major social roles of student, employee and mother empower them to overcome the difficulties they face in their lives. Giving more power to children with disabilities through education and to women with disabilities through employment and family life equips them not only to involve themselves in the functionings valued by society, but also enables people with disabilities to be seen as capable and contributing members of society; this empowers them, but it also empowers society.

This thesis examined the lives of employed women with disabilities and children with disabilities in relation to their roles and their social inclusion in education, employment, and motherhood. It used the theoretical frameworks provided by the capability approach, (family) quality of life, and social role valorisation to investigate the findings of the in-depth interviews and focus-group discussions.

In the following sections, the main findings of the four articles displayed in this thesis, are presented and discussed, followed by theoretical and methodological reflections. This is followed by a discussion of the contributions and implications of the research. Finally, suggestions are made for future research into the lives of women and children with disabilities in low and middle income countries (LMICs).

The research questions discussed in the thesis were:

1. What are the challenges and opportunities that women with disabilities in LMICs face in participating meaningfully in education, employment and family life
2. What factors determine the participation of women with disabilities in LMICs in the important social roles of student, employee and mother, as well as their achievement of valued goals in life?
3. What are the opportunities and difficulties in education and employed life experienced by high achieving Ethiopian women with disabilities?
4. How do opportunities and difficulties in the life experiences of high-achieving Ethiopian women with disabilities affect their achievement of valued goals in life?
5. What are the life experiences of intimacy and marriage, pregnancy, giving birth, and motherhood of women with disabilities in Ethiopia?
6. How do children with disabilities experience social inclusion?
7. What are the primary caregivers' beliefs, attitudes and behaviours in relation to the social inclusion of their children with disabilities?

In the following paragraphs the main findings from the four different studies that together answer these research questions are summarised.

6.2 Main findings

6.2.1 Challenges and opportunities for women with disabilities

In Chapter 2, the literature from academic and non-governmental organisations' databases on the challenges and opportunities for women with disabilities in LMICs was systematically reviewed. This review focused particularly on education, employment and motherhood. It is necessary to understand the opportunities and challenges faced by women with disabilities in LMICs in their meaningfully participation in education, employment and family life, as these areas are crucial for the articulation of inclusive development theories and the design of appropriate (family) quality of life interventions. The main questions addressed in this chapter were:

> *What are the challenges and opportunities that women with disabilities in LMICs face in participating meaningfully in education, employment and family life?*
>
> *What factors determine the participation of, women with disabilities in LMICs in the important social roles of student, employee and mother, as well as their achievement of valued goals in life?*

The review highlighted that women with disabilities in LMICs have several difficulties in participating and succeeding in education, employment and motherhood. The review also showed that the major challenges faced by women with disabilities in participating in the three identified important social roles and the achievement of valuable life goals are: limited accessibility, stigma and lack of support. These challenges hamper women with disabilities from achieving and using their capabilities and participating in education, employment and family life. Finally, poverty was found to exacerbate the factors that hinder women with disabilities from participating in these social roles and succeeding in major life domains.

Two frameworks—social role valorisation and the capability approach—which can help to understand the disability inequality of women with disabilities in LMICs, were used to analyse the reviewed articles. The conceptualisation of the review in terms of social role valorisation identified three themes (education, employment and motherhood), related to three social roles (student, employee and mother), which are interrelated in that each one supplements the others. In terms of the capability approach, the review revealed the importance of evaluating what an individual can do, or is able (and enabled) to do, and what they actually do.

The review suggests that there is a need to increase awareness and understanding among governments, educators, employers, and families about the life experiences of women with disabilities in developing countries and their ability (and right) to participate, given adequate conditions. Furthermore, the review demonstrated the underrepresentation of studies in LMICs, considering the intersectionality of poverty, gender and disability. The available studies were often small case studies; hence, there is a need for more longitudinal and intersectional studies. The final suggestion from the review is that there is a need to build a disability component into all aspects of national and international development efforts (Bruyère, Looy & Peterson, 2005; Groce, Kett, Lang & Trani, 2011).

6.2.2 The paradox of disability and the need to empower women with disabilities

In Chapter 3 a qualitative study on the life experiences of women with disabilities related to education and employment was presented. Qualitative, semi-structured in-depth interviews were used to explore the experiences of educated employed women with disabilities in Addis Ababa. The main research questions addressed in this chapter were:

> *What are the opportunities and difficulties in education and employed life experienced by high achieving Ethiopian women with disabilities?*
>
> *How do opportunities and difficulties in the life experiences of high-achieving Ethiopian women with disabilities affect their achievement of valued goals in life?*

The major finding of this part of the study is that women with disabilities from rural areas or poorer families had relatively better opportunities for education than their siblings; a disability paradox. These women with disabilities were sent to institutions for children with disabilities and received education because they were less likely to marry or to be required to do household chores. These education opportunities enabled them to obtain employment. The women experienced difficulties becoming employed and within employment, such as accessing facilities and acquiring equipment or devices. However, paradoxically, the experience of overcoming these challenges empowered these women—i.e., the women reported feeling strong, self-confident and self-reliant, which gave them pride and helped them to feel valued as citizens. These women perceive a high quality of life, despite their experiences due to their disabilities that resonate the ‘disability paradox’ that is also described by Albrecht and Devlieger (1999). In their study, they found that people with disabilities can experience a ‘good or excellent quality of life’ in the presence of ‘negative attitude, perceptions and ambivalent behaviour’ (p. 978-979).

Although the women with disabilities interviewed have achieved a relatively high level of accomplishment, the findings indicate that there are different challenges at different levels of attainment, such as stigma-related discrimination and limited opportunities in education and employment. Moreover, the findings of this study indicate that women with disabilities face more difficulties in both public and private spheres than women without disabilities. These include difficulties in accessing adequate housing, health care, education, vocational training and employment.

The study also found that women with disabilities experience being treated as helpless objects of pity and are subjected to hostility and exclusion. Hence, they are hampered in empowerment and denied the enjoyment of their fundamental human rights and freedoms, such as the right to equality in being employed and making promotion and to equal pay for equal work. Finally, the study found that women with disabilities experience barriers that can lead to situations in which they receive less care than women without disabilities.

6.2.3 The grace of motherhood

In Chapter 4, the experiences of women with disabilities in relation to their personal accomplishments in marriage, pregnancy and birth were examined, answering the following research question:

> *What are the life experiences of intimacy and marriage, pregnancy and giving birth, and motherhood of women with disabilities in Ethiopia?*

By analysing the interviews with mothers with disabilities about their experiences in intimacy, marriage, and motherhood, the challenges they faced were revealed, as well as how the interviewees managed their motherhood responsibilities. This chapter looked at how social roles and expectations present additional challenges for women with disabilities in their capacity as mothers.

In the analysis, this chapter integrated the capability approach, the family quality of life approach, and the disability culture perspective. The part of the chapter on the capability approach recognises intimacy, pregnancy and motherhood as capabilities that are highly valued by women with disabilities. In relation to the family quality of life approach, the results show that family is an important resource for achieving the quality of life of women with disabilities, as in Ethiopian culture married life with children is highly valued. The pride that these women took in motherhood particularly was found to be empowering, not only because they were able to take up a role that is highly valued for women in Ethiopian society, but also because it enabled them to strive for other valued capabilities in life as well. Moreover, intimacy and motherhood, as conceptualised from a disability culture perspective, provide women with disabilities with a unique set of expertise. This perspective contrasts with the common cultural perspective of mothers with disabilities, who are subjected to general social stigma and have to deal with unjustified assumptions about their parenting capabilities.

The study showed that motherhood, for all of the respondents, despite adding challenges to their daily life, has empowered the women and given them 'grace'. In other words, motherhood enables women with disabilities to give and receive love, trust, and respect, as well as take on responsibilities and receive social support, all of which make them feel valued. The study also highlighted the need for intimacy, regardless of society's denial of this need in women with disabilities through negative societal attitudes regarding relationships, pregnancy, and child-rearing for such women. The other major findings of this study are about the inaccessibility of health centres and the ignorance and negative attitudes of physicians. These challenges exist even though women with disabilities who have experienced motherhood may have developed some resilience and have been empowered by participating in the valued role of being a mother.

6.2.4 Social inclusion of children with disabilities

Chapter 5 presents the findings of a qualitative study on the experiences of children with disabilities in relation to their social inclusion. Two focus group discussions were held with children with disabilities and their primary caretakers, mostly their mothers. The major research question of this chapter were:

> *How do children with disabilities experience social inclusion?*
>
> *What are the primary caregivers' beliefs, attitudes and behaviours in relation to the social inclusion of their children with disabilities?*

This part of the study conceptualised the findings by integrating the concept of family quality of life and the capability approach, using the themes of being, belonging and becoming. The participants described 'being' in relation to: the impact of having a disability, coping with the disability, and being confronted with all the irrational beliefs around disability. The participants agreed that their general (physical) condition affects the social inclusion of children with disabilities. Regarding the 'belonging' of children with disabilities, the focus group discussants referred to the aspects of the physical, social and community environment that influence inclusion, illustrated by most of the participants by their experiences of (not) belonging at school. The 'becoming' theme covered growth becoming, practical becoming and leisure becoming, describing the actual activities that can be carried out at school, at home and in relation to leisure. The majority of children with disabilities who participated in the focus group discussion described accomplishment in education as their major growth becoming.

Family in an Ethiopian context refers mostly to the people who live in the household, which include not only the nuclear family (mother, father, and children), but also members of the extended family (grandparents, aunts, uncles, cousins, and others). Moreover, these family members most often also form the primary caregivers of children with disabilities. Accordingly, the opportunities and challenges of one member of a family become the strength or weakness of the whole family. The findings of the study indicate that children with disabilities are excluded for 'being different' from other community members, as they cannot perform certain 'functionings' (Terzi, 2005). Moreover, the study found that children with disabilities are often hardly socially included, except that most participants in the focus group discussions indicated that they are highly included in their families and peer groups (of other children with disabilities). Thus, the findings suggest the need for support for the whole family in order to reinforce the capabilities and improve the quality of life of children with disabilities and their families.

6.3 Theoretical reflections

6.3.1 Capability approach

The capability approach focuses on what people are effectively able to do and to be; that is, their capabilities (Robeyns, 2005). Sen, the founder of the capability concept, argues that evaluations and policies should focus on what people are able to do and be, on their quality of life, and on removing obstacles in their lives so that they have more freedom to live the kind of life that they value.

In conceptualising and applying the capability approach, this thesis explores women and children with disabilities' capabilities; that is, their effective opportunities to undertake the actions and activities that they want to engage in and to be who they want to be. This 'being' and 'doing', which Sen calls 'functionings', together constitute the quality of life for women and children with disabilities. This thesis designates functionings as: studying, working, being mothers, in other words, being socially included in valued social roles. The distinction between achieved functionings and capabilities is between what is realised and what is possible, in other words, between achievements and the freedom (or option) to achieve. What is ultimately important is that women and children with disabilities have the freedom or achievable opportunities (capabilities) to lead the kind of life that is valued by society and by themselves (as part of society) and to be the person they want to be. Once they have these opportunities, they can choose the option(s) they value most. For example, women and children with disabilities should have the opportunity to be part of a community and participate in social activities, but, if they prefer to stay within their own circle, they should also have this option.

Thus, using the capability approach, this thesis weighs policies based on their impact on the capabilities of women and children with disabilities. It asks whether women and children with disabilities are, for example, socially included and whether the means or resources necessary for this capability are present, such as access to education, employment, and motherhood. Experiencing a valued life is important for women and children with disabilities, and for their families, a topic that is further discussed in the next paragraph.

6.3.2 Family quality of life

Families have always been important for people with disabilities, mostly for providing support as main caregivers. At the same time, living with a family member with a disability can enrich family quality of life (Chiu, Kyzar, Zuna, Turnbull, Summers & Aya, 2013), which reflects the disability paradoxes identified in Chapter 3. In this thesis, the reciprocity of family relationships and the value of living with disability became clear. Employed women with disabilities earn income for their family of origin, mothers with disabilities are proud of their children and vice versa, and mothers with disabilities take care of their children and sometimes get assistance from their children.

Life domains that are universally important for everyone, also apply to people with disabilities and their family members. These domains are explained in Chapter 5 of the thesis, in exploring the social inclusion of children with disabilities, as ‘being’, ‘belonging’ and ‘becoming’. These functionings are highly intertwined, while at the same time reinforcing each other. For example, a blind child who does not have a friend without a disability (belonging) may think that her disability (being) is the reason for her isolation. At the same time her friendship with other blind children may be strong (belonging) and she may feel valued when she plays with her best friends (becoming), thereby enhancing her quality of life.

In the extended family life that Ethiopians experience, aspects of being, belonging and becoming in families are even more important. In Family Quality of Life, these aspects are reflected in domains that include emotional aspects of family life, physical and material well-being (being), relationships among and between family members (belonging), and parenting and disability-related support (becoming) (Samuel, Rillotta & Brown, 2012; Hoffman et al., 2006).

Throughout this thesis it is indicated that family life is negatively impacted by poverty, for instance poor infrastructure and, consequently, inaccessible roads and buildings, and the absence or very limited availability of disability-related support. On the other hand, positive impact was demonstrated in family relations and emotional aspects of family life, where family social values, such as having children and being a mother in mutual responding relationships were chief. Children with disabilities indicated that they can do what others do in school if they are equally included and have equal access as others. In the focus group discussion, the children with disabilities mentioned that they and their family members are affected due to the scarcity of educational resources, such as Braille books for blind students, accessible roads and disability-friendly toilets in schools, which sometimes forces students with disabilities not to drink water when they go to school.

6.4 Methodological reflection, strengths and limitations

There are limited studies available on disability in low income countries generally (Mitra, 2013; Naami, 2014). The available literature mainly discusses the challenges that women with disabilities face in various arenas (Dartnall & Jewkes, 2013; Plummer & Findley, 2012). In contrast, this thesis explored both the challenges and opportunities faced by educated employed women with disabilities. Furthermore, there is limited literature on the experiences and potential of employed women with disabilities in low income countries such as Ethiopia. This study showed the success of women with disabilities in Addis Ababa, Ethiopia, despite the hardships they have faced.

The studies in this dissertation are not without their limitations. Firstly, the educated employed women with various disabilities who participated in the first round of interviews (Chapter 3), which were conducted to explore their education and employment experiences, were selected only from Addis Ababa metropolitan area. Moreover, to access educated employed women with disabilities, snowball sampling was used. This limits the generalisability of the results of the study. For instance, participants were not classified based on similar level of education or profession (the participants have different levels of education). Hence, it is recommended that future research be conducted on women with a particular education level (such as master's level) or profession (such as schoolteacher), using a mixed method approach (quantitative and qualitative). Such research could also incorporate women with disabilities in rural areas and those who are uneducated.

Because in Ethiopia most people live in rural areas where the living standard is relatively low, compared to the capital, Addis Ababa, the differences in cultural and living standard between cities and rural areas of Ethiopia may produce different results. This was not taken into account in the research design. It would be interesting to further investigate these differences by studying women with disabilities in the rural areas of the country where there is less awareness and accessibility (education, employment and roads), and where the challenges faced by women with disabilities are expected to be more severe.

Moreover, the participants were all employed women with various physical disabilities. Hence, this study was limited in scope to employed disabled mothers; it would be interesting and comparative to focus on the motherhood experiences of women with disabilities who are unemployed. In addition, the participants had different marital status and different levels of family and other support. Knowing more about the experiences of children of women with disabilities with different marital statuses would lay a framework for assessing the needs and support required by the family members of mothers with disabilities. Thus, the study points to the need for more research on women with disabilities who live in rural areas, are unemployed, have different marital statuses, and different family living arrangements.

An intriguing finding of this study was that children are a source of pride, but also a source of practical support for mothers with disabilities. Mothers often claimed that their children were wonderful, and understood them well. Yet, they also claimed that their children did not have a different life than children with mothers without a disability. This tension is also something that could be looked at in future research. A similar finding emerged in the focus group discussions with primary caregivers: they reflected on what in their lives had been affected negatively (e.g., siblings bullied, family members experienced exclusion) and positively (e.g., the satisfaction family members get due to the progress of their children with disabilities). So a general overarching area for future research is the consequences of having a family member with a disability for other family members and how to support the capabilities of family members. Future research should, therefore, look at the support needs of family members of mothers with disabilities.

In relation to the social inclusion of children with disabilities, the participants of the two focus group discussions—children with disabilities and their primary caretakers—were selected from NGOs under one umbrella NGO from Addis Ababa metropolitan areas. Again, this makes generalisation risky. Moreover, the children with disabilities who participated in the study all receive some kind of support from NGOs, hence, the study does not consider children with disabilities who do not receive help, other than from their families.

A final recommendation for future research would be to conduct studies in close cooperation and partnership with persons with disabilities and their families, for example, in a participatory research design (Cochran, Marshall, Garcia-Downing, Kendall, Cook, McCubbin & Gover2008; Nind, 2014). The research agenda should be composed of topics raised by diverse stakeholders including (families of) women and children with disabilities, and be designed and conducted in collaboration with schools, employers, health care centres and policy makers.

6.5 Implications for policy and practice and future research recommendations

The employed women with disabilities interviewed for this thesis have overcome barriers and discrimination, which their counterparts - uneducated, unemployed and unmarried women with disabilities - are dealing with presently. The education and employment experiences of these women can inspire other women and children with disabilities by showing them that it is possible to be educated and employed, even in the presence of hardships. The strength of the women with disabilities interviewed enables them to be role models (Dawn, 2014) for other women with disabilities in LMICs. Consequently, the results of this thesis can help NGOs, international organisations, and other interested parties by giving them information about the real problems of Ethiopian women with disabilities, as the current literature on disability in LMICs is mostly based on experiences in western industrialised countries (Mitra., et al, 2013)

The findings of the study points to the need for equal opportunities, and then empowerment and leadership (Eide & Ingstad, 2011) for women with disabilities. Fulfilment of this need is a long way ahead for women with disabilities in LMICs such as Ethiopia. In countries that are now more affluent, in the past, women with disabilities were pitied, ignored, condemned and even hidden away in houses (Morris, 2014). In Ethiopia, especially in the rural areas where cultural norms are firmly in place, children and women with disabilities are still pitied, ignored, condemned, and hidden away. This is compounded by the intersection of poverty, gender and disability, which calls for special attention to be paid to the complexity of the phenomena to ensure social justice. Thus, creating knowledge and raising awareness that children and women with disabilities have abilities, needs and interests, like anyone else, may move the disability movement forward. For this, countries would need to develop conceptual interpretations that build on positive elements in their existing culture and context (Eide, Loeb, Nhiwatiwa, Munthali, Ngulube & Van Rooy, 2011), which would make such knowledge easier for society to internalise and accept.

Furthermore, conceptual clarity on how and why children and women with disabilities are excluded is needed before effective solutions for overcoming social exclusion can be put in place. However, such clarity need not mean adopting one internationally-accepted interpretation.

To advance the rights of children and women with disabilities and their development in Ethiopian society, and other developing country contexts, it is essential that their perspectives be included in all aspects of work for children and women's empowerment, and that all work on disability incorporates a gender perspective. Without the meaningful participation of women with disabilities in the disability dialogue (Yeo & Moore, 2003), developments may not reach the most disadvantaged women with disabilities. Therefore, exploring the life experiences of women with disabilities from a gender perspective in Ethiopia, as was done in this study, is important.

These kinds of messages from employed mothers with disabilities can teach society about the needs and potential of women with disabilities to be educated, employed and mothers. Furthermore, this reinforces the need for families to send their children with disabilities to school.

Ethiopia has a constitution and legislation that aims to provide equal rights for people with disabilities. Yet how to bring the legal framework into practice and change the lives of women and children with disabilities is a difficult quest. Future research could study what are important parameters that help making legislation and policy interventions effective.

Finally, I would like to summarise the ideas for future research mentioned in this dissertation paper, but not investigated.

In this thesis, the capability approach and the family quality of life concept were mainly applied separately in analysing the data collected on the lives of mothers and children with disabilities in Ethiopia. It is recommended that in a secondary analysis of the data, the concepts will be used more integrative. Both concepts attribute (dis)advantage from a contextual point of view, with freedom of choice, related opportunities and personal and cultural values as underlying principles that influence perceived well-being and quality of life (Burchardt & Hick, 2016; Brown, Faragher & Rhonda, 2014; Samuel, Rillotta, & Brown, 2012; Wolff & De Shalit, 2007; Sen, 1999). The shared responsibility of people and their social context, an important principle in the capability approach, resonates well with the principle of family quality of life, as families are important for people with disabilities, and impact on the lives of all members of a family in both positive and negative ways.

Primary caretakers, predominantly mothers, but also one uncle and the head of a NGO, participated in the focus group discussions. The research aimed to describe the experiences of children with disabilities in relation to social inclusion. The extent to which these experiences also apply to the siblings of children with disabilities cannot be estimated. It is quite possible that the impact on the social inclusion of siblings of children with disabilities resembles or varies from that of children with disabilities, as is reflected in the scarce literature on siblings of children with disabilities in developed countries (see: http://siblingleadership.org/research/). Therefore, it would be interesting to focus on the experiences of siblings in future research and examine their social inclusion. Generally speaking, it is important to consider all family members of children with disabilities in order to improve the quality of life of the whole family.

Some scholars have determined that there are still women and children with disabilities in Ethiopia who are hidden away by their families for fear of stigmatisation (Tefera & Van Engen, 2016). Hence, it is difficult to know the exact number of women and children with disabilities in Ethiopia (and in other developing countries). Insufficient research has been conducted on the abilities and inabilities of people/women/children with disabilities in LMICs. Thus, throughout Ethiopia, and in other developing countries, there is the need for more research on the life experiences of women and children with disabilities, including on discrimination before and after employment.

6.6 Conclusion

This study focused on the challenges and opportunities for women with disabilities in LMICs to participate and succeed in education, employment and motherhood. It aimed to provide a better understanding of the life experiences of educated disabled women in Ethiopia by focusing on the opportunities resulting from their disabilities, as well as the role that obstacles play in the lives of successful disabled women. The intimacy and marriage, pregnancy, birth, and motherhood experiences of women with disability in Ethiopia were also explored. In addition, the study investigated the social inclusion of children with disabilities in Addis Ababa, Ethiopia and how this affects their achievement of valued life goals. The theories of capability approach, (family) quality of life, social role valorisation and disability culture perspectives were used to investigate the lives of women and children with disabilities.

The study consisted of a systematic review of the literature, together with interviews and focus group discussions. The following findings can be drawn from the results of the study:

1. Women with disabilities in LMICs have severe difficulty participating and succeeding in education, employment and motherhood due to a number of interrelated factors such as hindered access, stigma, cultural practices and lack of support resulting in poor accessibility, discrimination and prejudice.
2. High achieving women with disabilities in Ethiopia had access to different opportunities, while facing hardships at the same time, resulting in paradoxes including: the paradox of disability and educational opportunity, the paradox of separation from family and success, the paradox of hardship in obtaining employment and related opportunities and strength, the paradox of disability hardships and self-confidence and self-reliance, the paradox of disability and improved quality of life, and the paradox of support and dependency.
3. Women with disabilities in Ethiopia also face negative societal attitudes regarding relationship, pregnancy, and child-rearing. Other challenges relate to the accessibility of health care centres, in addition to the ignorance and negative attitudes of physicians. The thesis also highlights how rewarding the experience of motherhood is for mothers with disabilities, even if they face challenges at every step of their experience, because of society's prejudices.
4. The existence of challenges to the social inclusion of children with disabilities should be recognised, and these challenges are reflected in their capabilities. There is a need for assistance and support for the family members of children with disabilities in order for them to achieve a good quality of life. Moreover, the involvement of the wider community is greatly needed to support children with disabilities and their families to enhance the capabilities of such children and to improve family quality of life.

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Appendices:

I. Tables

Summary of studies included in the review (Study and sample information, key excerpts of sections on education, employment and motherhood, moderators/conversion factors). (Table 1).

Author(s)	Study and sample information	Education	Employment	Motherhood	Moderators/ conversion factors
Braathen, Kvam. (2008A)	Qualitative research in Malawi using focus groups and interviews This article is based on a pilot study conducted in Malawi in 2006 that intended to uncover episodes of violence and abuse against women and girls with disabilities and furthermore to explore the mechanisms behind such acts. The stories of 23 women with disabilities were obtained through in-depth semistructured interviews that covered, among other topics, aspects of sexual abuse experienced by or known to these women. ***page 5***	The informants stressed that adapted education for women with disabilities would allow them to become more economically independent and be better able to refuse the advances of unserious suitors**.** ***Page 5***		In adulthood, several had experienced what they themselves defined as sexual abuse: Men came and wanted to "marry" them. When the woman became pregnant, the man disappeared and left her alone. Women with disabilities are often regarded as asexual and therefore "clean" (Groce, 2003). ***page 5*** At the same time, the women expressed their belief that their disability made them less attractive. In that regard, they also concluded that women with a disability often had fewer expectations and made fewer demands on the qualities of the husband. ***Page 15***	
Braathen & Kvam. (2008B)	Qualitative research in Malawi using focus groups and interviews	The women had faced many difficulties in relation to their education. These difficulties were not mainly because they were women, but because of their disabilities.Most schools in Malawi are neither adapted for nor accessible to people with physical impairments and inclusive education is rare. ***page 466*** that education made women with disabilities more selfconfident. ***page 466*** Nearly all the women stressed the importance of self-reliance for women with disabilities. ***Page 466*** They said that women should have a job and earn their own money, be able to take care of themselves and be less reliant on men**.** ***Page 466***		Some said that women with disabilities often have fewer expectations of a potential husband. One woman had found it difficult to find a man who wanted to marry her: ***page 467*** Some men are known to seduce women and propose marriage in order to have sex with them, but as soon as the women become pregnant the men disappear. ***page 468*** It is important for women to be able to fulfil their duties as women, but sometimes their impairments stand in the way of them doing their tasks ***page 468***	**Support:** While several of the informants had experienced discrimination and exclusion because of their impairments, most of the women had been well taken care of and were treated equally by their closest family and friends. They had a strong wish to be empowered through education and employment. ***page 2***
Dhungana. (2007)	Qualitative resaerch in Nepal: interviews	Disabled women are denied access to education, health services, vocational training and employment and welfare programs that are available for disabled men in Nepal. ***Page 135*** The educational status of physically disabled women is very low and it was not surprising they were excluded from employment. Lack of educational opportunities was the core reason for job exclusion. ***Page 136***	Disabled women are denied access to education, health services, vocational training and employment and welfare programs that are available for disabled men in Nepal. ***Page 135*** The educational status of physically disabled women is very low and it was not surprising they were excluded from employment. Lack of educational opportunities was the core reason for job exclusion. ***Page 136***	Women with disabilities encounter further discrimination as they are denied opportunities to marriage and family life. *page 135* Men do not prefer to marry disabled women because they are considered incapable of looking after family life. Additionally, there are misconceptions that the presence of disabled woman brings bad luck to the family. ***page 135***	
Emmett, & Alant. (2007)	Review in developing countries: First, the article reviews some of the data on women with disabilities in the United States and other industrialised countries, where existing data are most comprehensive. ***Page445*** Secondly, the article locates disability within the context of other social inequalities and disadvantages such as poverty, race and family structure. The complex interconnection of issues such as these have implications not only for families or households in general, but also for women in particular. The role of disability and gender is then considered within the context of developing countries, where conditions such as pervasive poverty, lack of services, and limited recognition of women's rights have profound implications for both women and people with disabilities. ***Page 446***	girls with disabilities receive less care and food, have less access to health care and rehabilitation services and may have reduced access to education and employment opportunities. ***Page 455***		Women with disabilities sometimes also have poorer marriage prospects than disabled men, and can be at risk of being physically and sexually abused. *page 455* disabled women experience the same oppression as non-disabled women, but often without even the status that women traditionally receive as mothers or wives. In addition, disabled women experience more discrimination than other women from being unable to live up to the demanding ideals for womanhood imposed by society'. ***page 455***	

Frohmader, & Ortoleva. (2013)	International conference paper This Briefing Paper examines the sexual and reproductive rights of women and girls with disabilities in the context of the future development agenda Beyond 2014 and Post 2015. ***Page2*** This Paper examines some of the key sexual and reproductive rights violations experienced by women and girls with disabilities around the world. It includes a discussion of intersectionality and multiple identity, recognising that this reality is important to any examination of the sexual and reproductive rights of women and girls with disabilities. It provides an analysis of the cycle of accountability in relation to the sexual and reproductive rights of women and girls with disabilities, looking at the dimensions of responsibility, answerability and enforceability.			Right to autonomy and self-determination – the right of everyone to make free and informed decisions and have full control over their body, sexuality, health, relationships, and if, when and with whom to partner, marry and have children - without any form of discrimination, stigma, coercion or violence. However, women and girls with disabilities throughout the world have failed to be afforded, or benefit from, these provisions in international, regional and national legal frameworks, standards and agreements. Instead, systemic prejudice and discrimination against them continues to result in multiple and extreme violations of their sexual and reproductive rights, through practices such as forced and/or coerced sterilisation, forced contraception and/or limited or no contraceptive choices, a focus on menstrual and sexual suppression, poorly managed pregnancy and birth, forced or coerced abortion, termination of parental rights, denial of/or forced marriage, and other forms of torture and violence, including gender-based violence. ***Page 2***	
Groce , Kett , Lang & Trani. (2011)	Review of theoretical constructss and data: international level. This article reviews existing knowledge and theory regarding the disability–poverty nexus. Using both established theoretical constructs and field-based data, it attempts to identify what knowledge gaps exist and need to be addressed with future research. ***page 1493*** This article reviews the current literature with regard to poverty and disability (particularly in the context of developing countries), building upon earlier work where the contours of the debate were outlined,3 as well as on country-specific studies presented utilising the capabilities approach,4 with a view to suggesting avenues for further research. The article also discusses some of the inherent challenges in developing appropriate and effective indicators by which disability issues in poverty alleviation initiatives might be evaluated***. page 1494***		Mitra and Sambamoorthi find in the case of the rural labour market in India that men with disabilities received lower wages than non-disabled counterparts, after controlling for a series of socioeconomic factors.1 ***page 1496*** Poor work opportunities: those who are chronically poor often find it xtremely hard to secure long-term sustainable employment, which is often exacerbated by poor health status and the lack of formal educational qualifications. Likewise, the large majority of people with disabilities are either unemployed or under-employed.38 ***page 1499***		
Gupta. (2013)	Descriptive paper on how the legislation benefits women with disabilities in India. *Secundairy data:* Most legislations on disability, including the Persons With Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 in India, do not contain any provision specifically addressing the concerns of women with disabilities.[16] The CRPD engages with the issue of multiple discrimination by adopting the twin track approach. ***Page 3***	Women and girls with disabilities fare less well in the educational arena than either their disabled male or nondisabled female counterparts.[67] Education is deemed less important for girls in the Indian society as they are not expected to become breadwinners. Disability limits their opportunities even more. Many girls with disabilities are not only denied access to education, but are also hidden away, as disability is perceived as a stigma.[68] ***Page 11***	There is dual stigmatization of disabled women as they are affected by negative stereotypes of both women and people with disabilities.[74] There are vast disparities in the labour force participation rates of women with and without disabilities, and between women with disabilities and men with disabilities.[75] Stereotypes frame disabled woman as unable to fulfil either the traditional role of homemaker or the newer role of wage earner.[76] Due to the double stereotyping, they are denied work even in the areas traditionally occupied by women, like nursing, teaching, etc. ***Page 12***	Women with disabilities are not expected to have relationships and are perceived as asexual.[54] Due to such perception, they have been denied the roles associated with womanhood, including the role of being a mother. ***Page 9*** Women with disabilities, especially cognitive disabilities, have been stereotyped as being incapable mothers.[56] ***Page 9***	
Kassah, Kassah & Agbota. (2013)	Qualitative research in Ghana, using in-depth interviews and focus group discussions	Our informants revealed that they also faced neglect when it came to their schooling. Though they all started school, none of them were able to complete it. ***page 668*** A lack of educational opportunities for disabled women therefore ‘‘deepened the vicious cycle of exclusion, deprivation and vulnerability . . .’’ [42]. ***page 668*** According to Reiser [41], parents and other family members are reluctant to prioritize the educational needs of their disabled children, often because of a belief that educating the disabled child is a waste. This is because they will not be able to work and look after their elderly parents. ***page 668***		The denial of participation in intimate relationships is another social abuse-related issue raised by our informants. All of them, with the exception of Celia, were forced out of their love relationships by their in-laws. ***page 668*** Family members of partners of disabled women in Ghana often encourage the social abuse of disabled women, because they view them as burdens to the man and the family [6]. ***page 668*** In Ghana, the inability of some disabled women to live up to the expectations of the traditional female role make them vulnerable to social abuse. When disabled women are assigned devalued roles, as in the case of our informants, it may result in poor treatment by other members of society [43]***. page 668***	

Kiani. (2009)	Qualitative research in Cameroon, two focusgroups, 1 rural 1 city(n=24) and one set of semistructured interviews with the use of participant observation (n=12) ***page 2***	As explained earlier, many girls with disabilities were not sent to school by their parents due to physical barriers, attitudinal barriers or lack of family finances. Participants stated that another reason why some parents discontinued the schooling of their daughters was that many months and sometimes years of schooling were lost while girls were in treatment, making it difficult for them to return to school. Participants stated that girls who did not get an education grew up to believe that they could not contribute to society and they lacked confidence and self-esteem as adults. P***age 524***	A major concern of participants was their difficulty in obtaining employment due to discrimination by employers. One participant noted: You may drop off your application when the boss is not around. You fill the application and they see the English is very presentable, very qualified for the job. When you come for the interview and they discover you are physically disabled, they conclude that you cannot do the job. ***page 525***	One of the main challenges that all participants shared was finding a suitable marital relationship. One woman stated that many men were afraid of disabled women due to the false belief that disability was contagious. Other women felt that African cultural norms expect women to perform household chores while bringing in an income. This creates a difficult expectation for women with disabilities and they are seen by men as 'unfit'**.** ***page 524***	
Lamichhane. (2012A)	Mixed research in Nepal: qualitative and quantitative: The study design is based on mixed method. Mixed method not only draws the strengths but also minimize the weakness of both quantitative and qualitative techniques (Johnson and Onwuegbuzie 2004). The quantitative part of the study has been analysed descriptively whereas thematic content analysis has been used for qualitative interviews. ***page 313***	Table 2. Average years of schooling and share of schooling based on type of impairment. ***Page 316*** Among 347 participants who attended school have an average of 8.8 years of schooling. Comparatively, UNESCO data indicates that the average for Nepali children is 9.4 years. Participants with hearing impairments had an average of 6.9 years, participants with visual impairments had an average of 9 years, and participants with physical impairments had the highest average of 10.9 years. ***Page 315*** The results indicate that participants with hearing impairments had the fewest years of schooling, compared with those with visual and physical impairments. Among the total participants, 2.7% had informal education, 20.9% gave up after completing five years of schooling. ***Page 315***			Accessibility: Unavailability of schools was another factor cited as a limiting the access to education. ***Page 319*** **Support:** People with visual and hearing impairments faced the inadequacy of support systems in schools, whereas participants with physical impairments mainly faced difficulties caused by physical barriers, such as inaccessible buildings and the lack of safe, accessible roads. Additionally, the barriers faced in common by the participants were financial barriers, resulting from parents' poverty; and barriers resulting from parental attitude, social stigma and lack of awareness. ***page 2***
Lamichhane. (2012B)	Mixed research in Nepal: quantitiative and qualitative : People with three kinds of disabilities (visual, hearing, and physical) were included in this study. We randomly selected interview participants from the name lists of the five main disability-related national organizations in Nepal: Nepal Association for the Welfare of the Blind, National Association of Physically Disabled Persons, Nepal Association of the Deaf and Hard of Hearing, Nepal National Federation of the Deaf and Hard of Hearing, and the Nepal Association of the Blind. Out of a total of 993 potential participants who met our age and impairment criteria,423 respondents were randomly selected using proportionate stratified random sampling, in which the individuals' sex and type of impairments were employed to set each stratum. ***page 474***	Access to education, and in particular higher education, is instrumental for people with disabilities to achieve gainful and satisfying employment ***page 2***	Results indicated that people with hearing, physical or visual impairments often dominated a specific employment sector. Numbers of people with physical, hearing and visual impairments were respectively large in the non-governmental organization sector, restaurants, and local schools. *Page 2* The low number of women in the workforce is probably related to traditional attitudes towards gender roles in Nepal, particularly for employees of the current generation. Women with disabilities therefore face some additional challenges.***Page483***		
Mitra, Posarac, & Vick.(2012)	Quantitative study **in developing countries**. This paper uses for the first time internationally comparable data to draw an economic profile of persons with disabilities in 15 developing countries. Disabled and non-disabled participants from all these countries. Comparable data: It used a common questionnaire in nationally representative populations with different modules to assess the health of individuals in various domains, health system responsiveness, and household expenditures and living conditions. ***Page 3***	Seventh, at the individual level, in most of the countries included in the study, persons with disabilities have lower educational attainment and experience lower employment rates than persons without disabilities. ***Page 13***	Seventh, at the individual level, in most of the countries included in the study, persons with disabilities have lower educational attainment and experience lower employment rates than persons without disabilities. ***Page 13***	This study presents a snapshot of the economic wellbeing and poverty situation of working-age persons with disabilities and their households in 15 developing countries in Africa, Asia, Latin America, and the Caribbean. ***Page 1*** *Paper includes:* Table with % No primary school completion and % Non-Employed of disabled vs. non-disabled people on **page 8.**	
Moodley, & Graham. (2015)	Review in South Africa This article draws on the secondary data analysis of Wave 2 (2011) data from the National Income Dynamic Study (NIDS) (South African Labour and Development Research Unit (SALDRU), 2014). (N=16898) ***Page 26***	In terms of education, people with disabilities had an average of 2.5 years less education than non-disabled people (p<0.05). Furthermore, women with disabilities acquired the lowest levels of education, as seen in Table 1. ***page 27*** Gender was not a significant contributor to education levels. **page 27**	Table 3 demonstrates that people with disabilities are significantly less likely to be employed. They are also less likely to be unemployed. This is because they are far more likely not to be economically active. Black people with disabilities face a double exclusion and Black women with disabilities fare the worst in terms of labour market outcomes. ***page 28*** Low levels of employment of people with disabilities means that those with disabilities are likely to experience increased disillusionment in the labour market, leading to greater likeliness of opting out of the labour market. ***page 31***		

Morrison, Basnet, Budhathoki, Adhikari, Tumbahangphe, Manandhar, Costello,& Groce. (2014)	Qualitative study using semistructured interviews in **Nepal** we purposively sampled married women with different impairments who had delivered a baby in the past 10 years from different topographical areas of the district. We also interviewed maternal health workers. We compared our findings with a recent qualitative study of non-disabled women in the same district to explore the differences between disabled and non-disabled women.	-	-	Many disabled women were embarrassed and this often prevented them from telling their in-laws about their pregnancy: It's difficult to tell to parents-in-law isn't it? I was frightened to tell my in-laws(Physically impaired woman, plains). ***Page 1135*** However, embarrassment tended to affect decisions about place of birth. Women were afraid of bringing shame on their family if they showed their body during institutional delivery. ***page 1135*** In general, physically disabled women reported the most difficulty in performing housework, and caring for themselves and their families. ***Page 1136***	**Accessibility:** ***Page 1135*** Generally,,health workers found it most difficult to provide services to women with hearing and speech impairments, as they could not communicate easily with them. **Stigma:** ***Page 1135*** To some extent, rude behaviour of health workers was expected, and disabled women did not link the way they were treated with their impairment. **Support:** ***Page 1136*** Not all disabled women received support, and some reported being teased or treated differently. A few women felt isolated, and may have expected to be excluded.
Naami , Hayashi & Liese. (2012)	Qualitative research in Ghana: exploratory and phenemenological focus groups		These perceptions about women not only limit their participation in the labor market but also affect the way institutions treat them in terms of remuneration. Their limited participation in the labor force results in their limited power and influence in decision-making both at home and in the community (CWMG 2004). Moreover, women with disabilities in Ghana, as their counterparts across the globe, are regarded as asexual (Boylan 1991; Lonsdal 1990), further diminishing their status as women. ***Page 193***		
Naami. (2015)	Quantitative study in Ghana, exploratory results. One hundred and ten (110) persons with disabilities of working age from the three regional capitals of the Northern Sector of Ghana; Tamale, Wa, and Bolga participated in the study.		1. Women, in general, are less valued in the labour market, as shown by inequality in participation in the labour force, pay, the kind of jobs they have, and the positions they hold. 2. Persons with disabilities also experience several challenges on the job, including negative perceptions about their capabilities, discrimination and exclusion, irrespective of the employment sector and disability type. 3. Unemployment rates were higher for women with disabilities 16 (59.3%) than for men with disabilities 11 (40.7%), 4. although not statistically significant, women with disabilities experience more of the barriers to the employment of persons with disabilities identified in this study than their male counterparts: (1) discrimination, (2) lack of start-up capital and (3) inadequate skills.		
Opini. (2010)	Review in Kenya It draws on existing literature and on a narrative of the experiences of one disabled academic in a Kenyan university to highlight some of the forms of discrimination that disabled people have to cope with in their workplaces. ***Page 2***	Unfortunately, the majority of the disabled people in Kenya remain either illiterate or have progressively become so after their rudimentary primary schooling. This is mainly due to scarcity of resources, which forces poor parents to make choices on how to invest the limited resources available. ***page 274***	What is happening, however, is that there has been an increasing trend of channelling disabled persons into acquiring vocational skills for skilled and semi-skilled work, including tailoring, clerical work, leather work, carpentry or masonry, driving and car repair, which are sometimes not aligned with the country's contemporary job market needs (Nkinyangi and Mbindyo 1982). Consequently, there is a serious lack of fit between existing forms of vocational training and employment opportunities. ***page 274*** Hence, you have Roggero et al. (2006) observing that 'while perceptions of disability may limit employment opportunities, it is the lack of competitive 'employable' skills among the disabled people that gives employers justification for discriminating against them' (p. 647, emphasis added). ***page 274*** This limited access to education makes it difficult for people with disabilities to compete for the limited available job opportunities. ***page 275***		

Ortoleva. (2010)	International review Part II then reviews the evolution and legal framework of the United Nations Women, Peace and Security strategy, beginning with the post-World War II peace framework and outlining the genesis of the various United Nations resolutions. These include the conclusions of the Beijing Declaration progress review in 2000 (Beijing + 5), which highlighted the urgent need to include women in peace-keeping operations and peace-building activities. ***Page 85*** Part III further explores the intersection of the United Nations Convention on the Rights of Persons with Disabilities (CRPD),9 the United Nations Convention for the Elimination of All Forms of Discrimination Against Women (CEDAW),10 and the United Nations Women, Peace and Security framework.11 ***Page 86***		Women with disabilities have low employment rates, experience discriminatory hiring and promotion, do not receive equal pay for equal work, and are frequently steered into segregated and less remunerative occupations.54 ***Page 92***	Numerous issues affect women with disabilities disproportionately when compared to men with disabilities and women without disabilities. These include health, education, employment, violence, family rights, marriage, housing, and participation in public life, all of which are exacerbated by war and observed globally. ***Page 84*** Other forms of gender-based violence include murder, sexual slavery, child prostitution, forced pregnancy, forced sterilization, acid burnings, and so-called "honor killings." 96 ***Page 98***	**Accessibility:** Inaccessible health care services are also a significant barrier for women with disabilities, with respect to physical inaccessibility of facilities, staff who lack the skills to communicate with women with various disabilities, and those who view them as asexual when it comes to the provision of sexual and reproductive health care services.56 ***Page 93***
Parnes, Cameron, Christie, Cockburn, Hashemi, & Yoshida. (2009)	Review in developing countries (LMIC): literature review We critically examined the broad literature in the area of disability and development and in this article we identify the key issues which emerged. Most of the data were collected from existing literature in the academic and practice settings and from the publications of key NGOs and governments.***page 1***	UNESCO estimates that 90% of children with disabilities in the Global South do not attend school [28]. As a result of this lack of access, the global literacy rate for adults with disabilities may be as low as 3%, and even lower for women with disabilities [29]. ***page 1174*** Together with children who were poor, indigenous or living in slums, persons with disabilities were identified in the report as being 'at a systematic disadvantage' [31]. ***page 1174***		She will have less access to health care and rehabilitation services, fewer educational and employment opportunities, and little hope of marriage. ***page 1174*** A 2004 survey in Orissa, India, found that 100% of the women and girls with disabilities were physically abused at home, 25% of women with intellectual disabilities had been raped and 6% of women with disabilities had been forcibly sterilised [14]. ***page 1174***	
Salome, Mbugua, & Ong'eta. (2013)	Qualitative and quantitative research in Kenya: questionnaire-based interview methods The study employed mixed methods data collection through the use of both qualitative and quantitative methods to produce comprehensive data on the plight of FSWD in Higher Education. A case study of a higher institution of learning was undertaken, whereby the FSWD were sampled. The case study approach allows for an intensive or an in-depth investigation of the problem at hand and brings out a deeper understanding of the situation (Kombo and Tromp, 2006). The target population was 13 FWSD who were purposively sampled from the institution of higher learning. The study utilized questionnaires, interviews and Focus Group Discussion to collect rich and indepth data regarding GBV experiences of the respondents. ***page 5***	Research observes that despite some helpful laws, policies and systems of practice in some countries compared to their disabled male or non-disabled female peers, women with disabilities: are less educated; experience higher rates of unemployment; are more likely to be abused; are poorer; are more isolated; experience worse health outcomes; generally have lower social status. ***Page 4*** The research further revealed that the respondents also experienced various forms of GBV while undergoing basic levels of education. This was more for those who went to mainstream public schools, whereby they shared being teased and taunted not only by their peers, but also some of the teachers, who told them that they were incapable of achieving high grades at school as compared to the other students in spite of their cognitive ability. This mitigated on their self-esteem and concentration in class. ***Page 8***	Research observes that despite some helpful laws, policies and systems of practice in some countries compared to their disabled male or non-disabled female peers, women with disabilities: are less educated; experience higher rates of unemployment; are more likely to be abused; are poorer; are more isolated; experience worse health outcomes; generally have lower social status. ***Page 4*** On the other hand, women with disabilities are less likely to participate in the labor force, the employment rate of non-disabled men as 85 per cent compared with 75 per cent for non-disabled women. The employment rate for disabled men is 52 per cent and disabled women 48 per cent in the world. ***page 2***		
Simkhada, Shyangdan, van Teijlingen, Kadel, Stephen & Gurung. (2013)	Qualitative research in Nepal Four hundred and twelve married women of reproductive age (aged 15–49 years), from four villages in two different parts of Nepal, who had delivered a child within the last 24 months preceding the study, completed a standard questionnaire. ***page 1***	A recent UN report suggests that children with disabilities in Nepal face diverse and imposing barriers to obtaining a basic education. Schools are physically inaccessible, teachers are inadequately trained, and some children are denied admission to neighbourhood schools. ***page 2***			**Stigma** The attitudes of respondents towards disability were also explored (Table II). The majority (85.4%) of women thought that the disabled people can go to school and sit on committees (81.5%). Nearly three quarters of the respondents thought that the disabled can marry (69.7%) or have children (66.3%). ***page4*** The attitudes of respondents towards disability were also explored (Table II). The majority (85.4%) of women thought that the disabled people can go to school and sit on committees (81.5%). Nearly three quarters of the respondents thought that the disabled can marry (69.7%) or have children (66.3%). ***Page 3***
Tuomi, Lehtomäki & Matonya (2015)	Qualitative research in Tanzania Information on enrolment and demographic data concerning students with disabilities was obtained via the Dar es Salaam University Resource Centre. Women with disabilities were invited to participate in the research. All were eager to be interviewed and gave their informed consent for participation in the research. The data were collected through semi-structured interviews of six women with disabilities as a pilot of wider qualitative research on the experiences of university women with disabilities. ***page 205***				**Accessibility:** The first barrier to participation and success in higher education is admission to the university. Throughout their educational careers, the women told that poverty made it easy to feel defeated and to give up.In addition to determination, three areas of focus were found which enhanced the access of the women to higher education: an encouraging family environment; motivation from primary and secondary school teachers; and sufficient financial support. **--> these 3 are the primary reasons for women not finishing their education *page 207***

					Support: ***page 208*** Peer networking and study groups enabled the university women with disabilities to live and study with non-disabled students and were significant for the women's success. The influence of peer-networking spanned many arenas of university life, such as academic studies, free-time activities and involvement in university politics. Teachers' encouragement and support were seen as crucial for the full participation of the women. They played a significant role in facilitating the respondents' participation by providing materials, setting up special equipment and adapting their teaching style to meet their needs.
UN General Asssembly. (2012) Veenendaal. (2008)	Qualitative international research: The Paper was prepared by the Department of Economic and Social Affairs (DESA), with inputs from UN Women, to facilitate the discussions at the 5th Session of the Conference of States Parties, particularly the informal dialogue on women with disabilities, to be held on 13 September 2012. ***Page 1***	Women with disabilities have limited access to education and consequently demonstrate lower educational attainment compared to the general population. ***Page 2***	Women with disabilities have often only limited access to vocational and skills development training and experience lower rates of employment. Where employed, women with disabilities face lower wages and rates of job retention and progression. ***Page 2***		**accessibility:** Women with disabilities often lack access to services essential to the full enjoyment of their human right and fundamental freedoms. ***page 1*** Women with disabilities experience multiple discrimination, based both on gender and their disability, and therefore often must confront additional disadvantages in comparison to men with disabilities. ***Page***
Veenendaal (2008)	Review on international level: The principle legislations are: 1) UN Convention on the rights of persons with disabilities (UN, 2006) 2) United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities (UN, 1993) 3) Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities (2006) 4) Vienna Declaration / Programme of Action (1993) 5) ILO Convention 159 6) ILO Code of practice ***Page 6***	Many disabled persons live in rural areas where isolation means a scarcity or absence of educational services. Children with disabilities in isolated areas often remain uneducated due to prejudice, misunderstanding and the lack of special schools. ***Page11***	The lack of awareness among employers about the rights of persons with disabilities is an important obstacle to be overcome in securing employment. Employers see people with disabilities as less productive and costly in terms of assistive devices and reasonable accommodation. ***Page 13***		

Table 2 Background of interviewed educated employed women with disabilities

Name	Type of disability	Level of education	Profession
Interviewee 1	Legs problem (wheel chair user)	M.A in gender studies	Project coordinator
Interviewee 2	Legs problem (Crutch user)	B.A in Information communication technology (ICT)	System administrator
Interviewee 3	Blind	B.A in Sociology	Project coordinator on inclusion
Interviewee 4	Legs problem (Crutch user)	M.A. in Social work	Facilitator of a project
Interviewee 5	Legs problem	Diploma in Business information system	Cashier accountant
Interviewee 6	Partial Blind	M.A in Special needs	Assistant facilitator of a project
Interviewee 7	Partial Blind (very limited sight)	B.A in Local Language (Amaharic)	School teacher
Interviewee 8	Blind	Diploma in Language (Amaharic & English)	School teacher
Interviewee 9	Leg problem (uses stick)	High school Diploma in Natural science	Secretary and cashier
Interviewee 10	Right leg problem	Diploma in Accounting	Accountant
Interviewee 11	Legs problem (Crutch user)	M.A in Accounting and finance	Budget analyst
Interviewee 12	Right leg problem	Diploma in Business information systems	Cashier accountant
Interviewee 13	Legs problem (Crutch user)	Diploma in Secretarial science and office management	Secretary and cashier

Characteristics of the Interviewees (Table 3)

Name	Age	Marital status	Number of children	Role of father
A	35	Married	One	No support
B	29	Single	One	No support
C	34	Single	One	Financial support & visiting the child
D	38	Single	Two	No support
E	32	Single	One	No support
F	39	Divorced	Three	Financial support
G	32	Married	Two	Supportive
H	35	Married	Three	Supportive
I	28	Single	One	No support
J	27	Single	One	No support
K	35	Married	Two	Supportive
L	43	Single	Two	Supportive
M	30	Married	One	Supportive

Background of focus group participants: children with disabilities and primary caretakers of children with disabilities (Table 4)

Participant children with disabilities				Participant primary caretakers	
Name	**Gender**	**Age**	**Disability type**	**Name**	**Relationship**
C1	F	16	Blind	PC1	Mother of a child with hearing impairment
C2	F	17	Blind	PC2	Mother of two children with hearing impairment
C3	F	18	Blind	PC3	Owner of NGO for Blind children
C4	F	17	Blind	PC4	Mother of a Blind Child
C5	F	16	Blind	PC5	Uncle of a Blind child
C6	F	13	Wheel chaired	PC6	Mother of a child with leg problem
C7	M	15	Hearing impairment	PC7	Mother of a child with hands and legs problems & autistic
C8	M	16	Hearing impairment	PC8	Mother of a child with movement problem
C9	F	13	Hands and legs problem		

Appendix II: Interviews and focus group discussions Questionnaires

Interview Questions

Introduction

Interview Questions (1)

Introduction

Good (morning/evening). My name is Belaynesh Terera. I am a lecturer in the Addis Ababa University School of Commerce.

Thank you for participating in this important survey which is designed to study **Barriers for Career Development Opportunities of Disabled Women Employees in Ethiopia.** The survey is a research which is part of my PhD requirement in Tilburg University of Netherlands.

- In this survey, I will ask you questions concerning your career development. Specifically, I will ask you questions related to opportunities and barriers you might have encountered:
  - in your education
  - in your family life
  - in the community (society) and
  - in getting special support that you might have required to reach this level.

If it is alright with you, I would like to record this interview on a voice recorder in order to capture your responses accurately. In my field of study, it is important to write literal transcriptions of our conversations in analyzing the data. I would like to assure you that I will not disclose your personal identity in any reports or writings. If I use literal excerpts from the interview, I will first ask your permission to use the excerpts before I use it in any form. I like to assure you that I will not use your name, or organization or any information that identifies you in any report I will write. Our conversations will be confidentially stored in a locked storage place.

Unless, you have concerns, I like to proceed with the survey now.

Background Information

First, I would like to ask you about your personal information:

1. What is your Name?
2. How old are you?
3. What is your marital status?
4. Do you have any children?
    a. (Ask if answer is yes above) How many?
5. What is your highest level of education attained?
6. What was your field of study?
7. Which high school did you attend?
8. Which college or University did you attend?
9. Can you describe in what way you were disabled?
10. Can you tell me about the history of your disability,
    a. Whether you have always been disabled, or whether it developed, increased or decreased during your life?

Career/Developmental opportunities

11. Now I will ask you to describe the steps you took and obstacles or challenges you faced because of your disability in pursuing your career:
    a. First, please describe the steps that you took
    b. What obstacles that you encountered in relation to your disability
12. Now I will ask you about factors that influenced your career.
    a. What factors influenced you career positively?
    b. How about factors that influenced you career negatively?
13. Can you tell me about your educational experiences in your high school?
14. Can you tell about your educational experience in college or university?
15. Have you had role models or mentors? When and where? (in school/college and work place?)
16. How was your relationship with your peers in school/college/university?
17. Do you believe that the relation with your peers influenced you positively or negatively?
    a. Could you elaborate more on how that influenced you?
    b. Does it have any influence on your present personality?
18. What is your current position in your organization?
    a. How did you obtain your current employment position? (Communicated through media, applying by yourself or by any other means)
    b. Was it difficult to get this employment opportunity?
    c. If yes, why do you think this was?
19. What was the path you followed in your profession which lead you to your current position?
20. Do you like your present job?
    a. If no,

        i. What is the reason?
        ii. If you do not like your present, why are you staying in your present job?

21. Do you believe that you have attained what you expected to achieve in your career?
    a. If no, what do you think the reasons are?
22. What are the opportunities for further education after employment?
23. What are the barriers for further education after employment?
24. What other opportunities did you have on your job?
    a. Were the opportunities the same to all employees?
25. What other barriers did you have on your job?
    a. Were the barriers the same to all employees?
26. Do you believe that you can handle any responsibility on your profession?
    a. If no, can you tell me the reason why not?

Family Influence

27. Now I will ask you about family, friends and community support that may have helped with your career development.
    a. What were the roles played by your parents, brothers, sisters, and others extended family members?
    b. What were the roles played by your social network, such as friends and acquaintances?
    c. If married and/or have children, what were the roles played by your husband and/or children?

Social Support

Now, I will ask you about social support you might have experienced.

28. What is the extent that you experience support from your supervisor?
29. What is the extent that you experience support from your coworkers or colleagues?
30. Do you experience support from any of your friends?
31. Have you ever been treated differently because of your gender?
    a. If yes, please explain the circumstances?
    b. Do you believe that you had any support for your career development from government?
        i. If, yes, what kind of support did you receive?
        ii. How was this support provided?

Disability Impact

Now, I will ask you questions directly related to your disability and your career development

32. Can you tell me the opportunities you faced due to your disability on your career development?
33. Can you tell me the barriers you faced due to your disability on your career development?
34. Do you believe that you could do better if you were not disabled?
    a. If yes, to what extent do you think your disability affected your career development?
35. In general, in your opinion, what were the effects of your disability on your career development?

Poverty Impact

Now, I will ask you about the impact of economic factors and disability.

36. Do you believe that the limited resources of the country affected your career development?
37. Have you ever given priority in getting any limited resources due to your disability?
38. Have you received any support from the government, employer or any other organization to cover the expenses of high costs directly associated with your disability?
39. Would you describe the employment opportunity for disabled women in Ethiopia as poor, good or very good?
    a. If answered poor, do you consider the countries poverty as a major cause of poor employment?
    b. What other reasons do you think there are for the poor employment opportunities among disabled women in Ethiopia?
40. Do you have additional comments or remarks that we have not addressed in our conversation that relate to disabled women and their career development?

We now have concluded the survey!

Thank you very much for this interview. As agreed I will treat the information you provided extreme care and will keep it confidential. I hope to share my findings with you once the results are compiled and careful analysis is performed.

Interview Questions (2)

Introduction

Good (morning/evening). My name is Belaynesh Terera. I am a lecturer in the Addis Ababa University School of Commerce.

Thank you for participating in this important survey which is designed to study **The Challenges and Rewards of Motherhood: Experiences of Disabled Mothers.** The survey is a research which is part of my PhD requirement in Tilburg University of Netherlands.

- In this survey, I will ask you questions concerning your motherhood experience. Specifically, I will ask you questions related to the challenges and rewards of being a disabled mother.

If it is alright with you, I would like to record this interview on a voice recorder in order to capture your responses accurately. In my field of study, it is important to write literal transcriptions of our conversations in analyzing the data. I would like to assure you that I will not disclose your personal identity in any reports or writings. If I use literal excerpts from the interview, I will first ask your permission to use the excerpts before I use it in any form. I like to assure you that I will not use your name, or organization or any information that identifies you in any report I will write. Our conversations will be confidentially stored in a locked storage place.

Unless, you have concerns, I like to proceed with the survey now.

Background Information

First, I would like to ask you about your personal information:

41. What is your Name?
42. How old are you?
43. What is your marital status?
44. How many children do you have?

45. What is your highest level of education attained?
46. Can you describe in what way you were disabled?
47. Can you tell me about the history of your disability,
    a. Whether you have always been disabled, or whether it developed, increased or decreased during your life?

Challenges faced as a disabled mother

48. Can you tell me about being a disabled mother?
49. Can you explain about your relationship with your child/children?
50. How do your child/children feel about your disability?
51. Do you feel that your child/children miss things that they had to get because of your disability?
52. Can you share the most challenging aspects of being a disabled mother?
    a. Indoor activities
    b. Outdoor activities
    c. Mobility issues
53. Can you tell me about the health and safety issues of disabled mother in Ethiopia?

Experiences of other people's attitudes

Now I will ask you about social factors that influenced you in your motherhood responsibilities.

54. How do you describe the attitude of the society towards the motherhood of disabled women?
55. Can you share some of your experiences regarding your motherhood in relation with the society's attitude?

Positive aspects of being a parent/ Rewards of Disabled mothers

Now, I will ask you questions directly related to your disability and your motherhood experience

56. Can you tell me about your positive motherhood experience in relation with:

    a. Relationship
    b. Pregnancy
    c. After giving birth

57. Now I will ask you about family, friends and community support that may have helped your motherhood responsibility.

    a. What were the roles played by your parents, brothers, sisters, and others extended family members?
    b. What were the roles played by your social network, such as friends and acquaintances?
    c. If married, what were the roles played by your husband?

58. Do you have additional comments or remarks that we have not addressed in our conversation that relate to disabled women and their motherhood?

Would you please suggest some important issues which should be included in the interview?

We now have concluded the survey!

Thank you very much for this interview. As agreed I will treat the information you provided extreme care and will keep it confidential. I hope to share my findings with you once the results are compiled and careful analysis is performed.

Questionnaire for Focus group discussion in the Social inclusion of Children with Disability (3)

Introduction: Good morning/afternoon, my name is Belaynesh Tefera from Addis Ababa University School of Commerce. Thank you for taking the time to participate in this focus group discussion. The data gathered from this focus group discussion is used only for my PhD thesis which is done in Tilburg University of The Netherlands.

This focus group discussion is designed to assess your current thoughts and feelings about quality of social inclusion of Ethiopian children with disabilities. The focus group discussion will take no more than two hours. May I tape the discussion to facilitate its recollection?

Anonymity: Despite being taped, I would like to assure you that the discussion will be anonymous. The tapes will be kept safely and will be translated and transcribed word for word. The transcribed notes of the focus group will contain no information that would allow individual subjects to be linked to specific statements. You should try to answer and comment as accurately and truthfully as possible. If there are any questions or discussions that you do not wish to answer or participate in, you do not have to do so; however please try to answer and be as involved as possible.

Ground rules

- The most important rule is that only one person speaks at a time. There may be a temptation to jump in when someone is talking but please wait until they have finished.
- There are no right or wrong answers
- You do not have to speak in any particular order
- When you do have something to say, please do so. There are many of you in the group and it is important that I obtain the views of each of you
- You do not have to agree with the views of other people in the group
- Does anyone have any questions? (answers).
- OK, let's begin

Introductory Question

First, I would like everyone to introduce yourselves. Can you tell us you name, age (for the child participants).

Guiding Questions

To the children with disabilities

1. In what ways does your community/society include, or not include, you as children in activities, play groups and events?
2. How easily can you socialize with your peer groups in school, neighborhood or community?
3. Where do you prefer to be socially participate? Why.
4. Tell me about your participation in other activities, like education, culture, recreation, or spiritual activities?
5. What do you expect the ideal world for children with disability look like?
6. How can it be created?

To the mothers

1. How do you evaluate the social inclusion of your child?
2. What kind of social participation makes you more comfortable for your child?
3. What do you feel when your child socializes? Why.
4. What do you expect the ideal world for your children?
5. How can it be created

Concluding question

- Of all the things we've discussed today, what would you say are the most important issues you would like to express?

Conclusion

- Thank you for participating. This has been a very useful/successful discussion
- Your opinions will be a valuable asset to the study

- We hope you have found the discussion interesting
- If there is anything you are unhappy with or wish to complain about, please contact me later
- I would like to remind you that any comments featuring in this report will be anonymous

Poverty Impact

Now, I will ask you about the impact of economic factors and disability.

59. Do you believe that the limited resources of the country affected your career development?
60. Have you ever given priority in getting any limited resources due to your disability?
61. Have you received any support from the government, employer or any other organization to cover the expenses of high costs directly associated with your disability?
62. Would you describe the employment opportunity for disabled women in Ethiopia as poor, good or very good?
    a. If answered poor, do you consider the countries poverty as a major cause of poor employment?
    b. What other reasons do you think there are for the poor employment opportunities among disabled women in Ethiopia?
63. Do you have additional comments or remarks that we have not addressed in our conversation that relate to disabled women and their career development?

We now have concluded the survey!

Thank you very much for this interview. As agreed I will treat the information you provided extreme care and will keep it confidential. I hope to share my findings with you once the results are compiled and careful analysis is performed.

Appendix 3: Letter from Ethics Review Board, Consent form and letters

SCHOOL OF SOCIAL AND BEHAVIORAL SCIENCES
ETHICS REVIEW BOARD

Department of Tranzo
Prof. Dr J.J.L. van der Klink

Department Human Resource Studies Dr M.L. van Engen
Ms. B. Tefera Nidaw
Date
13 November 2017

Subject
Review research proposal

Date of your letter
6 November2017

Reference
EC-2017.81

Telephone
013 466 29 56

E-mail*erb@tilburguniversity.edu*

Dear Prof. van der Klink, Dr. van Engen, and Ms. Tefera Nidaw,

The Ethics Review Board (ERB) has discussed the revision of your research proposal '*The experiences of children with disabilities, and their mothers', and primary care takers' reactions towards the social inclusion of disabled children in Ethiopia'* and decided that the given suggestions and deliberations are mostly sufficiently dealt with. Please, make sure to remove the sentence: "I am aware that I can make any reasonable changes to this consent form." from the consent form which is directly below the authors' response letter, as well. There are no further ethical concerns, so you are allowed to execute your research (if you have removed the above mentioned sentence, you do not need to send in a new version).

The Board wants to draw your attention to the terms and conditions in the appendix.

If changes are made to the research protocol, you need to submit an amendment to obtain ethics approval again.

Sincerely,

Dr. Nina Kupper
Chair Ethics Review Board

Attachment(s)

1
The ERB retains the right to at any time revise its decision regarding the implementation and the WMO status of any research study in response to changing regulations, research activities, or other unforeseen circumstances that are relevant to reviewing any such study. T he ERB shall notify the principal researcher of its revised decision and of the reason or reasons for having revised its decision. (WMO: Wet medisch-wetenschappelijkonderzoek met mensen, Medical Research (Human Subjects) Act)

Focus Group Consent Form

Research project title: The Social inclusion of Children with Disability

- I agree to participate in the focus group discussion on social inclusion of children with disability of Ethiopia carried out by Belaynesh Tefera of the PhD candidate of Tilburg University, to aid with the research of the PhD thesis.

- I understand the aims of the project.

- I am aware of the topics to be discussed in the focus group.

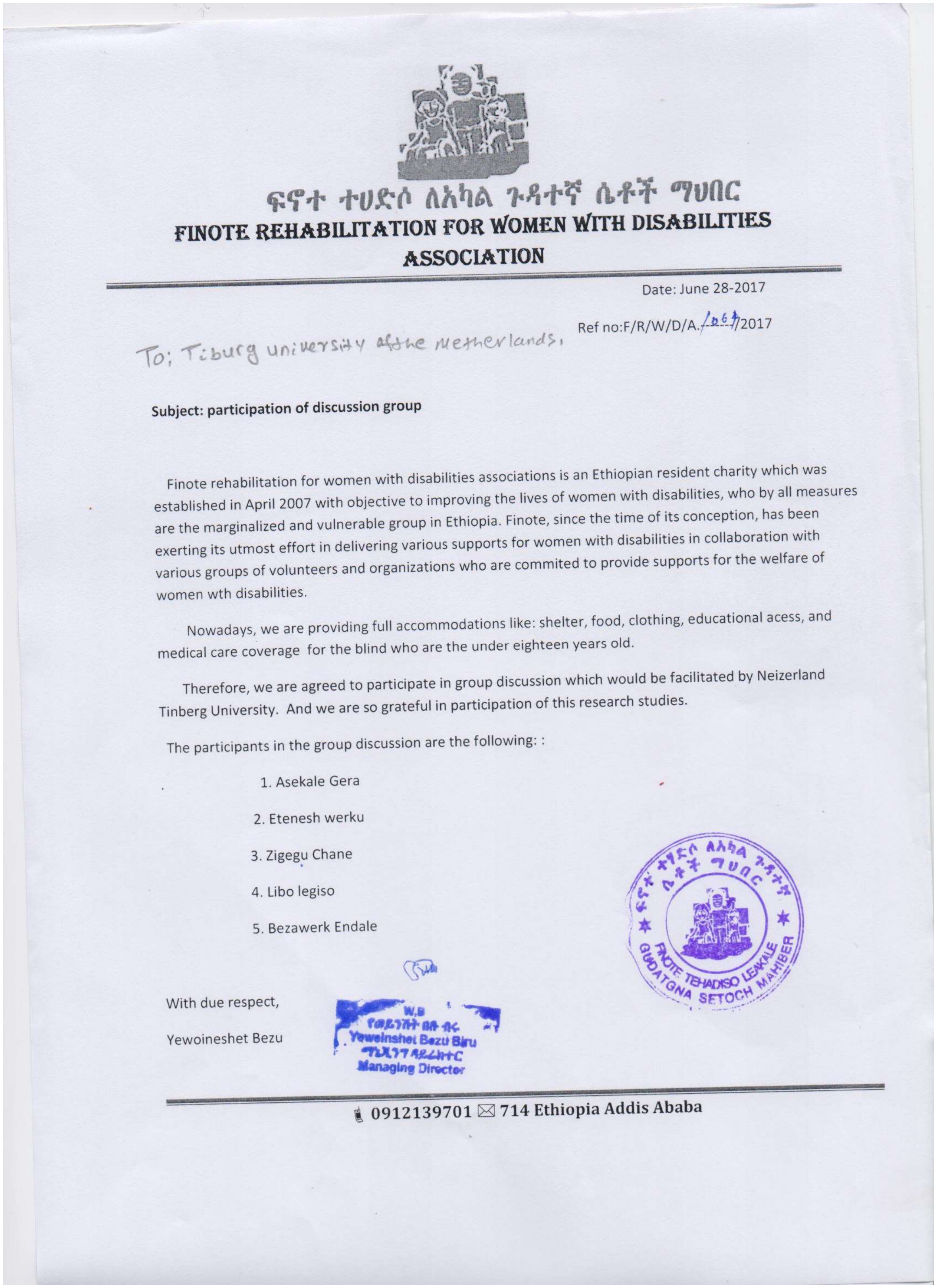
- I am fully aware that I will remain anonymous throughout data reported and that I have the right to leave the focus group at any point.

- I am fully aware that data collected will be stored securely, safely.

- I am fully aware that I am not obliged to answer any question, but that I do so at my own free will.

- I agree to have the focus group recorded, so it can be transcribed after the focus group is held.

____
Printed Name
____
____
Participants Signature
Date
____
____
Researchers Signature
Date



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FINOTE REHABILITATION FOR WOMEN WITH DISABILITIES ASSOCIATION

Date: June 28-2017

Ref no:F/R/W/D/A./064/2017

To; Tiburg university of the netherlands,

Subject: participation of discussion group

Finote rehabilitation for women with disabilities associations is an Ethiopian resident charity which was established in April 2007 with objective to improving the lives of women with disabilities, who by all measures are the marginalized and vulnerable group in Ethiopia. Finote, since the time of its conception, has been exerting its utmost effort in delivering various supports for women with disabilities in collaboration with various groups of volunteers and organizations who are commited to provide supports for the welfare of women wth disabilities.

Nowadays, we are providing full accommodations like: shelter, food, clothing, educational acess, and medical care coverage for the blind who are the under eighteen years old.

Therefore, we are agreed to participate in group discussion which would be facilitated by Neizerland Tinberg University. And we are so grateful in participation of this research studies.

The participants in the group discussion are the following: :

1. Asekale Gera
2. Etenesh werku
3. Zigegu Chane
4. Libo legiso
5. Bezawerk Endale

With due respect,

Yewoineshet Bezu

W.B
Yeweinshet Bezu Biru
Managing Director