

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 study is based on focus group discussions with children with disabilities and primary caregivers of such children. 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 areas of quality of life: being, belonging, and becoming. 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, and so improve their family quality of life.

Keywords: quality of life, capability approach, low- and middle-income countries (LMICs), Ethiopia, social inclusion

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Social inclusion is an important element of well-being for children (Biggeri, Ballet, & Comim, 2011). The World Bank (2013) defines it as “the process of improving the ability, opportunity, and dignity of people, disadvantaged on the basis of their identity, to take part in society” (p. 4). Social inclusion is a key component of the United Nations Convention on the Rights of Persons with Disabilities (Hendricks, 2007) and, as a stated right, is a legitimate goal for community-based services and support (Cobigo, Ouellette-Kuntz, Lysaght, & Martin, 2012).

People with disabilities face many barriers to full participation in society and are likely to face social exclusion (Islam, 2015) by family, friends, communities, and the government. In a study of 25 Belgian families, their social networks were found to comprise mainly family members and professionals (Steel, Poppe, Vandeveld, Van Hove, & Claes, 2011), although the latter are rare in developing countries (Samadi & McConkey, 2011). Children with disabilities and their family members often 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 QOL and psychological well-being (Gupta & Singhal, 2005).

Furthermore, children with disabilities often need support and guidance from their families long after they have reached adulthood (Aldersey, Francis, Haines, & Chiu, 2017). This draws attention to the ongoing need to support parents and primary caregivers across the lifespan of the person with a disability (Bayat, 2007; Singer, Ethridge, & Aldana, 2007).

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

Although there are indications that low 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, even in developed countries, where there are in general numerous studies on social inclusion, research on the social inclusion experiences of children with

disabilities 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 children with disabilities and their families (King et al., 2003; Schalock, 2004).

The specific research questions addressed were: (a) How do children with disabilities experience social inclusion?, and (b) What are the primary caregivers' beliefs, attitudes, and behaviours in relation to the social inclusion of their children with disabilities?

Method

Conceptual Framework

Social inclusion was conceptualised for the purposes of this study using the theory of FQOL and the capability approach. Social inclusion is a critical component of QOL (Schalock, 2004; Verdugo, Schalock, Keith, & Stancliffe, 2005) and gives children with disabilities opportunities to be involved in valued life domains (Sen, 1992). It also contributes to FQOL. This investigation is based on the QOL domains identified by Raphael, Renwick, Brown, and Rootman (1996) that are also applicable to FQOL. The two constructs, capability approach and FQOL, are explained using the three themes of being, becoming, and belonging, as those themes have social contexts that are important to the QOL of children with disabilities and their family members (Brown, Cobigo, & Taylor, 2015).

The capability approach, developed by Nobel 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 — “beings and doings people have reason to value” (Sen, 1992, p. 40) — that are feasible for a person to achieve. The capability approach looks at how people can attain goals that are valuable to them. The approach states explicitly that it is the shared responsibility of the individual and the social context to facilitate the building up of a person's capability set so that they can be enabled to achieve a valuable life. This makes a claim about society that is in line with the claims of the World Bank (2013) and Cobigo and colleagues (2012).

According to Sen's (1999) capability approach, resources (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 using them, converting them into outcomes. For Sen, equity in opportunities and capabilities (i.e., the “freedom to achieve” the important goals that people have) is central, 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 — on what they can achieve.

Moreover, the desire to be valued in one's society, for example by peers, has traditionally been explained by the existence of natural instinct: the need for social inclusion is considered a normal part of every person's identity. In addition, being socially isolated means having limited access to external supports (Chenoweth & Stehlik, 2004), which makes children with disabilities dependent only on their families; this in turn affects FQOL. Being, belonging, and becoming, the domains of FQOL identified by Raphael et al. (1996) and used in this paper, explain the effects of social inclusion (and exclusion) experiences on children with disabilities and their families. Based on the same authors, these three themes are further classified into subthemes:

- being: physical, psychological, and spiritual;
- belonging: physical, social, and community; and
- becoming: growth, practical, and leisure.

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 areas of FQOL suggested by Raphael et al. (1996) appear to fit nicely with Sen's (1999) capability model.

Focus Group Participants and Setting

The methodology used was focus group discussions with children with disabilities and with 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) chose the participants from those who had been put forward by various nongovernmental organisations (NGOs) under the umbrella of ENDAN. The representative met the children with disabilities and caregivers, and informed them 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 to 17 years old, and one was 18 years old; two were deaf (male), two had leg problems (both female, one a wheelchair 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; the discussion with primary caregivers lasted 2 hours and 6 minutes.

In what follows, the result of the analyses of the two focus group discussions are presented together and the most expressive excerpts are used for all themes and subthemes.

Procedures

At the beginning of each session, a moderator (a blind woman) facilitated the focus group discussions and elaborated on what social inclusion means in the context of the study. 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. The focus group discussions were performed in Amharic (the native language of both the interviewer and interviewees). The recorded focus group discussions were transcribed verbatim and translated from Amharic to English by a language professional. The first author carried out the final check on the translations.

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 on behalf of 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 both as a courtesy and to make the nature of the study and the researchers' intent clear to the participants. Ethical approval was granted by the School of Social and Behavioural Sciences Ethics Review Board of Tilburg University, The Netherlands.

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 FQOL and the capability approach, focusing on the social inclusion experiences of children with disabilities. Second, themes were identified based on the manuscripts of the two focus group discussions. Third, the identified themes were reframed using the three domains of being, belonging, and becoming.

The analysis process began with translating the voice-recorded focus group discussions into manuscripts, followed by repeated readings of the text data by the authors. The next step was to identify specific text segments related to the objectives and to code them (Thomas, 2006).

To create categories, the segments of text were labelled by bringing together similar and repeated passages, taking care to minimise overlap and redundancy among the categories; we then created a model that incorporated the most important categories (Attride-Stirling, 2001; Green et al., 2007). From these, themes were identified (LaRossa, 2005). These categorised themes from the general coding were then recategorised (Edmunds & Brown, 2012) using the three domains of being, belonging, and becoming. 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, the subthemes within each of being, belonging, and becoming were applied. 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 were categorised under the QOL indicators of being, belonging, and becoming (Raphael et al., 1996). The analysis also follows the interpretations given to being, belonging, and becoming by Raphael et al. (1996). The same authors explain that these three themes are intertwined, which was also observed in this study while categorising the excerpts under the three themes. In addition to the intertwined nature of the three themes, the focus group discussions resulted in overlaps between the themes 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 themes (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, ... impairment.”) relate to both being and becoming, while the subsequent statements (“The others laugh at me ... 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 the irrational beliefs around it. The participants agreed that the general physical condition or disability affects the

social inclusion of children with disabilities. Some child participants indicated that their disability barred 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)

This statement explains the impact that hearing impairment has on the social inclusion of the child. The participant reveals that he cannot communicate with people who cannot use sign language and that 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, the mother of a child with blindness:

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 was given by an educated physician, indicating the low level of awareness about disability in Ethiopia.

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

Someone from here goes with them when they [children with disabilities] 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)

This participant highlighted some of the misguided beliefs of physicians about children with disabilities, such as children with blindness, who are often considered incapable of performing simple tasks like undressing, and illustrates 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 mean 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 was always considered to be an inability and that people tried 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 the mother of a disabled child in a focus group discussion illustrates 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 judgements 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 that is 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 mother who was partially blind, and had a daughter with blindness, described the emotions she felt when they were 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 ones 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

Belonging describes the aspects of the physical, social, and community environment that influence inclusion. With regard 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 as long as 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, which they regard as necessary if they are to belong physically at school equally with other children:

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 was 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. The librarians use sign language and we cannot see and communication is very difficult, Thus, I should go and get it, what I want to communicate with the librarian with hearing impairment, written down. (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 avoids drinking when 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 of 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 something 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 illustrates 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 included 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 p.m. This is because there is nothing I can play with at home. (Child 7)

Another child explained that the belonging he had with his family members was traditional in the sense that they lacked 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 did 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 felt 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 had 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 other family members, who urged her to give her child to an organisation or abandon her:

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 related 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 that people with blindness had with the design, construction, and maintenance of footpaths, crossings, paved areas, and streets, and how these affected 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 used a wheelchair explained the need to accompany her child to school and back, even though the child believed that she could make the journey alone:

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 [the disability] is hereditary. (Primary caregiver 8)

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

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 believed that they were socially excluded in relation to access to health care centres. For example, a child with deafness explained that those who were deaf could not communicate with doctors in the health care centres, as no one there knew 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 person with deafness] 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 wheelchairs 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, a stylus, 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 widespread. 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 [a small amount of cash transfer for some families of children with disabilities], 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 section 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 the neighbourhood. 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 would contribute 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 faced in school. The first was the inaccessibility of schools, including the unavailability of slates and styluses for students with blindness, the inaccessibility of school buildings for students who used wheelchairs, and the limited number of teachers who could use sign language. These obstacles made it more difficult for children with disabilities to achieve their full growth potential in relation to "becoming" in education:

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, the 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 [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 handled some household chores, as her mother understood 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 knew about the presence of clubs in schools, they said that they did 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 was blind, said that she did not participate in school clubs: “There is a 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, and longer duration activities such as vacations or holidays.

Some of the children with disabilities revealed that they played 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 tried to play even if it did 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 wanted to take her child to a playground, but was limited because the playgrounds available in Addis Ababa were 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 FQOL and the capability approach. Data were gathered about social inclusion of children with various disabilities using two focus group discussions.

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, not only as a capability in itself, but also in order to achieve different capabilities or “functionings”, including leisure activities, communication, social activities, education, and mobility (Trani, Bakhshi, Bellanca, Biggeri, & Marchetta, 2011). However, not all of these capabilities 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., playmates leading a child who is blind to a ditch).

Children with disabilities are also excluded as being “different” from other community members, as they do not perform certain functions (Chenoweth & Stehlik, 2004). Children with disabilities reported that they did not participate in school clubs and organisations, seldom got together with peers outside the classroom, and were less involved in all school activities. This is because the school environment hinders the participation of children with disabilities and the resources needed to support their participation are inadequate (Coster et al., 2013). However,

society assumes that it is their incapacity that keeps them from participating in school activities. Those who have had the opportunity to participate in education take pride in it and have formed their own subgroups with siblings or with other people with impairments, which act as support groups for them.

These results suggest that the opportunities for, or capabilities and functionings of, children with disabilities in low-income countries such as Ethiopia are limited. This, in turn, affects the QOL of families of children with disabilities; hence the need for supporting the whole family, which helps to create favourable conditions 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 strengths of children with disabilities; despite all of the 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 a double challenge: meeting the financial and emotional needs of the entire family while coping with the demands of caring for a child with special needs, with fewer 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 the present 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. There are minimal 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 QOL 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 FQOL issues of children in low- and middle-income countries, particularly since the study incorporates the views both of children and of their primary caregivers.

Conclusion

QOL for families and their children with disabilities, with regard to achieving capabilities and valuable functionings, has emerged as a useful indicator of the success of 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 such children 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 when they have access to the necessary 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 important factors to address in improving 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 FQOL in terms of achieving capabilities as an indicator of the level of social inclusion of such children.
- 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.

References

- Aldersey, H. M., Francis, G. L., Haines, S. J., & Chiu, C. Y. (2017). Family quality of life in the Democratic Republic of the Congo. *Journal of Policy and Practice in Intellectual Disabilities, 14*(1), 78–86. [doi:10.1111/jppi.12189](https://doi.org/10.1111/jppi.12189)
- Attride-Stirling, J. (2001). Thematic networks: An analytic tool for qualitative research. *Qualitative Research, 1*(3), 385–405. [doi:10.1177/146879410100100307](https://doi.org/10.1177/146879410100100307)
- Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research, 51*(9), 702–714. [doi:10.1111/j.1365-2788.2007.00960.x](https://doi.org/10.1111/j.1365-2788.2007.00960.x)
- Biggeri, M., Ballet, J., & Comim, F. (Eds.). (2011). *Children and the capability approach*. London, UK: Palgrave Macmillan.
- Brown, R. I., Cobigo, V., & Taylor, W. D. (2015). Quality of life and social inclusion across the lifespan: Challenges and recommendations. *International Journal of Developmental Disabilities, 61*(2), 93–100. [doi:10.1179/2047386914Z.00000000092](https://doi.org/10.1179/2047386914Z.00000000092)
- Burnard, P., Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Analysing and presenting qualitative data. *British Dental Journal, 204*(8), 429–432. [doi:10.1038/sj.bdj.2008.292](https://doi.org/10.1038/sj.bdj.2008.292)
- Chamberlain, B., Kasari, C., & Rotheram-Fuller, E. (2007). Involvement or isolation? The social networks of children with autism in regular classrooms. *Journal of Autism and Developmental Disorders, 37*(2), 230–242. [doi:10.1007/s10803-006-0164-4](https://doi.org/10.1007/s10803-006-0164-4)
- Chenoweth, L., & Stehlik, D. (2004). Implications of social capital for the inclusion of people with disabilities and families in community life. *International Journal of Inclusive Education, 8*(1), 59–72. [doi:10.1080/1360311032000139467](https://doi.org/10.1080/1360311032000139467)
- Cobigo, V., Ouellette-Kuntz, H., Lysaght, R., & Martin, L. (2012). Shifting our conceptualization of social inclusion. *Stigma Research and Action, 2*(2), 75–84.
- Coster, W., Law, M., Bedell, G., Liljenquist, K., Kao, Y.-C., Khetani, M., & Teplicky, R. (2013). School participation, supports and barriers of students with and without disabilities. *Child: care, health and development, 39*(4), 535–543. [doi:10.1111/cch.12046](https://doi.org/10.1111/cch.12046)
- Divan, G., Vajaratkar, V., Desai, M. U., Strik-Lievers, L., & Patel, V. (2012). Challenges, coping strategies, and unmet needs of families with a child with autism spectrum disorder in Goa, India. *Autism Research, 5*(3), 190–200. [doi:10.1002/aur.1225](https://doi.org/10.1002/aur.1225)
- Edmunds, S., & Brown, G. (2012). Doing qualitative research in dentistry and dental education. *European Journal of Dental Education, 16*(2), 110–117. [doi:10.1111/j.1600-0579.2011.00734.x](https://doi.org/10.1111/j.1600-0579.2011.00734.x)

- Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*, 5(1), 80–92. [doi:10.1177/160940690600500107](https://doi.org/10.1177/160940690600500107)
- Green, J., Willis, K., Hughes, E., Small, R., Welch, N., Gibbs, L., & Daly, J. (2007). Generating best evidence from qualitative research: The role of data analysis. *Australian and New Zealand Journal of Public Health*, 31(6), 545–550. [doi:10.1111/j.1753-6405.2007.00141.x](https://doi.org/10.1111/j.1753-6405.2007.00141.x)
- Gupta, A., & Singhal, N. (2005). Psychosocial support for families of children with autism. *Asia Pacific Disability Rehabilitation Journal*, 16(2), 62–83.
- Heiman, T. (2002). Parents of children with disabilities: Resilience, coping, and future expectations. *Journal of Developmental and Physical Disabilities*, 14(2), 159–171. [doi:10.1023/A:1015219514621](https://doi.org/10.1023/A:1015219514621)
- Hendricks, A. (2007). UN Convention on the Rights of Persons with Disabilities. *European Journal of Health Law*, 14, 273–280.
- Islam, M. R. (2015). Rights of the people with disabilities and social exclusion in Malaysia. *International Journal of Social Science and Humanity*, 5(2), 171–177. [doi:10.7763/IJSSH.2015.V5.447](https://doi.org/10.7763/IJSSH.2015.V5.447)
- King, G., Lawm, M., King, S., Rosenbaum, P., Kertoy, M. K., & Young, N. L. (2003). A conceptual model of the factors affecting the recreation and leisure participation of children with disabilities. *Physical & Occupational Therapy in Pediatrics*, 23(1), 63–90. [doi:10.1080/J006v23n01_05](https://doi.org/10.1080/J006v23n01_05)
- Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2016). Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families' lives. *Journal of Autism and Developmental Disorders*, 46(3), 942–953. [doi:10.1007/s10803-015-2637-9](https://doi.org/10.1007/s10803-015-2637-9)
- LaRossa, R. (2005). Grounded theory methods and qualitative family research. *Journal of Marriage and Family*, 67(4), 837–857. [doi:10.1111/j.1741-3737.2005.00179.x](https://doi.org/10.1111/j.1741-3737.2005.00179.x)
- Raphael, D., Renwick, R., Brown, I., & Rootman, I. (1996). Quality of life indicators and health: Current status and emerging conceptions. *Social Indicators Research*, 39(1), 65–88. [doi:10.1007/BF00300833](https://doi.org/10.1007/BF00300833)
- Samadi, S. A., & McConkey, R. (2011). Autism in developing countries: Lessons from Iran. *Autism research and treatment*, 2011.
- Schalock, R. L. (2004). The concept of quality of life: What we know and do not know. *Journal of Intellectual Disability Research*, 48(3), 203–216. [doi:10.1111/j.1365-2788.2003.00558.x](https://doi.org/10.1111/j.1365-2788.2003.00558.x)

Sen, A. (1992). *Inequality reexamined*. New York, NY: Russell Sage Foundation.

Sen, A. (1999). *Commodities and capabilities*. Oxford, UK: Oxford University Press.

Shogren, K. A., & Turnbull, A. P. (2006). Promoting self-determination in young children with disabilities: The critical role of families. *Infants & Young Children, 19*(4), 338–352. [doi:10.1097/00001163-200610000-00006](https://doi.org/10.1097/00001163-200610000-00006)

Simplican, S. C., Leader, G., Kosciulek, J., & Leahy, M. (2015). Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. *Research in Developmental Disabilities, 38*, 18–29. [doi:10.1016/j.ridd.2014.10.008](https://doi.org/10.1016/j.ridd.2014.10.008)

Singer, G. H. S., Ethridge, B. L., & Aldana, S. I. (2007). Primary and secondary effects of parenting and stress management interventions for parents of children with developmental disabilities: A meta-analysis. *Developmental Disabilities Research Reviews, 13*(4), 357–369. [doi:10.1002/mrdd.20175](https://doi.org/10.1002/mrdd.20175)

Steel, R., Poppe, L., Vandavelde, S., Van Hove, G., & Claes, C. (2011). Family quality of life in 25 Belgian families: Quantitative and qualitative exploration of social and professional support domains. *Journal of Intellectual Disability Research, 55*(12), 1123–1135. [doi:10.1111/j.1365-2788.2011.01433.x](https://doi.org/10.1111/j.1365-2788.2011.01433.x)

Summers, J. A., Poston, D. J., Turnbull, A. P., Marquis, J., Hoffman, L., Mannan, H., & Wang, M. (2005). Conceptualizing and measuring family quality of life. *Journal of Intellectual Disability Research, 49*(10), 777–783. [doi:10.1111/j.1365-2788.2005.00751.x](https://doi.org/10.1111/j.1365-2788.2005.00751.x)

Thomas, D. R. (2006). A general inductive approach for analyzing qualitative evaluation data. *American Journal of Evaluation, 27*(2), 237–246. [doi:10.1177/1098214005283748](https://doi.org/10.1177/1098214005283748)

Trani, J.-F., Bakhshi, P., Bellanca, N., Biggeri, M., & Marchetta, F. (2011). Disabilities through the Capability Approach lens: Implications for public policies. *ALTER-European Journal of Disability Research/Revue Européenne de Recherche sur le Handicap, 5*(3), 143–157. [doi:10.1016/j.alter.2011.04.001](https://doi.org/10.1016/j.alter.2011.04.001)

Trani, J.-F., Bakhshi, P., Kuhlberg, J., Narayanan, S. S., Venkataraman, H., Mishra, N. N., ... Deshpande, S. (2015). Mental illness, poverty and stigma in India: A case-control study. *BMJ Open, 5*(2), e006355. [doi:10.1136/bmjopen-2014-006355](https://doi.org/10.1136/bmjopen-2014-006355)

Valicenti-McDermott, M., Lawson, K., Hottinger, K., Seijo, R., Schechtman, M., Shulman, L., & Shinnar, S. (2015). Parental stress in families of children with autism and other developmental disabilities. *Journal of Child Neurology, 30*(13), 1728–1735. [doi:10.1177/0883073815579705](https://doi.org/10.1177/0883073815579705)

- Venkatapuram S. (2011). *Health justice: An argument from the capabilities approach*. Cambridge, UK: Polity Press.
- Verdugo, M. A., Schalock, R. L., Keith, K. D., & Stancliffe, R. J. (2005). Quality of life and its measurement: Important principles and guidelines. *Journal of Intellectual Disability Research*, 49(10), 707–717. [doi:10.1111/j.1365-2788.2005.00739.x](https://doi.org/10.1111/j.1365-2788.2005.00739.x)
- Wang, M., & Brown, R. (2009). Family quality of life: A framework for policy and social service provisions to support families of children with disabilities. *Journal of Family Social Work*, 12(2), 144–167. [doi:10.1080/10522150902874842](https://doi.org/10.1080/10522150902874842)
- World Bank. (2013). *Inclusion matters: The foundation for shared prosperity*. New frontiers of social policy (Advance ed.). Washington, DC: Author. Retrieved from <http://hdl.handle.net/10986/16195>
- Xu, Y. (2007). Empowering culturally diverse families of young children with disabilities: The double ABCX model. *Early Childhood Education Journal*, 34(6), 431–437. [doi:10.1007/s10643-006-0149-0](https://doi.org/10.1007/s10643-006-0149-0)