

Parental Support towards Children and Youngsters  
with an Intellectual Disability  
in Northern Tanzania

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# Parental Support towards Children and Youngsters with a Intellectual Disability in Northern Tanzania.

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## Abstract

**INTRODUCTION:** Children with intellectual disabilities who live in poverty are among the most vulnerable people on the planet. Organizations, like the Liliane Foundation, try to improve their development and wellbeing by addressing the child's (immediate) social environment. **BACKGROUND:** Parent-child relationships are known to be particularly important in the development of children, especially for those with an intellectual disability. One of the mechanisms which make up the parent-child interaction is social support. Research has showed that receiving social support is beneficial for a person's wellbeing and health, in particular for individuals who are facing a high number of stressors, like people with a disability. To be able to optimize the service provision of organizations like the Liliane Foundation, it might be valuable to get an insight into the practices of parental support and the motivations behind it. This study aims at explaining what kind of support parents in northern Tanzania provide towards children with an intellectual disability and what motivates or limits them in doing so. **METHODS:** Semi-structured interviews were conducted with 14 intellectually impaired children, their parents and professionals in three places in northern Tanzania. 12 families of children with a physical impairment were included as a control group. **RESULTS:** The parents were mainly concerned with assisting the child to overcome his/her problem, by encouraging and advising him/her about how to become a self-sustaining grown-up. They were less involved with enhancing the child's self-esteem or making him/her feel valued. Cultural traditions, beliefs and expectations about the child's future are most mentioned as important indicators for (a lack of) parental support. African parents expect their child to reciprocate the investment they put into the its development. When they don not render the child capable of doing so, they are less willing to spend time and resources in the child's development. **CONCLUSION:** To improve the parental support provision towards children with an intellectual sidability, it is recommended to improve the parents' beliefs about the child's capabilities and future perspectives.

*Keywords:* parent-child relationship, social support, intellectual impairment, northern Tanzania

# Introduction

According to the most recent figures from the World Health Organization around 15% of the world's population lives with a disability. Out of these people 150-200 million are under the age of 18. Because of the fast population growth these numbers are still growing (United Nations [UN], n.d.; Liliane Foundation [LF], 2014a). A staggering 80% of all people with a disability live in low- to middle income countries (UN, n.d.; LF, 2014a). The World Bank even states that 20% of the people living in poverty have some kind of disability (UN, n.d.).

Poverty can both be a cause of disability and a consequence of it: on the one hand, living in a deprived situation increases the chance of becoming disabled, for example because of poor prenatal care or lack of nutrients. On the other hand having a disability can lead to exclusion and a deprivation of income (World Health Organization [WHO], 2010a). A lack of (access to) resources and services, therefore, makes children with a disability in developing countries one of the most vulnerable minority groups.

The Liliane Foundation (LF) is a Dutch organization aimed at improving the lives and possibilities of this group. It was founded in 1980 by Liliane Brekelmans-Gronert; she established the LF to address the exclusion of children with a disability (CWD) who live in poverty. The main objective of the organization was, and still is, to provide assistance to children with disabilities in developing countries, in order to help them and their families to participate in the community, like everyone else (LF 2014a; LF 2014b). Their objective is to make children and youngsters with disabilities who live in poverty, participate equally and as fully as possible in their families and communities, so that their lives have the highest quality possible (LF, 2014a).

In 2014 the LF published their core strategy, which they call the Child Empowerment Strategy (LF, 2014a). It consists of two strategic focal points: the Child Development component and the Enabling Environment component. In the first component the focus is on improving the child's functionality by addressing the impairment and helping him/her become more resilient and self-aware. For example by providing a wheelchair for a child who cannot walk, or help them to get a proper, fitting education. With 'enabling the environment' they mean to address environmental barriers which hinder the participation of CWD in the society (LF, 2014a; LF, 2014b). These ideals are executed by the LF's partner organizations, i.e. small-scale local organizations who work directly with the target group.

The LF has integrated the Community Based Rehabilitation (CBR) guideline into its Child Empowerment Strategy. According to these guidelines (WHO, 2010a; WHO, 2010b) CWD and their families should be considered key stakeholders in the rehabilitation process of the child. Families can be powerful agents of change toward inclusion, participation and expectations of the CWD and can even affect the attitudes of the community (WHO, 2010b). Therefore, the LF wants to include families and, in particular, parents/caregivers in all stages of the rehabilitation process in order to promote the acceptance of

the child (LF 2014a). According to the WHO, *“the role of CBR is to support people with disabilities to have fulfilling relationships with members of their families and communities”* (WHO, 2010b, p.19). After all, these relationships are *“essential for personal growth and development”* (ibid).

One of the countries where the Liliane Foundation has local organizations to work on the improvement of the lives of CWD, is Tanzania. Even though many organizations have made efforts to improve their wellbeing, children and youngsters with an intellectual disability in Tanzania are still frequently mistreated, isolated and deprived of resources and services (Mbwilo, Smide & Aarts, 2010). To improve the services provided by these organization, it is useful to learn more about the lives of these children and youngsters. The three organizations visited for this research were all located in the north of Tanzania, i.e. in Moshi, Sengerema (in the Mwanza-region) and Musoma.

The LF acknowledges the importance of including the child’s family in the rehabilitation process. In practice, however, parents/guardians do not always seem to be as involved as the organization would like them to be (Mhanga, 2014). In order to improve the involvement of parents in the child’s empowerment, it is important to know what kind of support the children receive and which processes motivate or limit this support. Therefore, this research is trying to answer the questions: ‘In what ways do parents support their children with an intellectual impairment in northern Tanzania? And what motivates them to do so?’

In the next chapter I will explore the literature on the subject and try to define the concepts associated with it. Then, I will discuss the current research, which was executed in March and April 2015 in the northern Tanzanian cities of Moshi, Sengerema and Musoma<sup>1</sup>. After reflecting on the results a conclusion will be drawn and recommendations will be given.

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<sup>1</sup> The data for this study was collected in collaboration with Susan van Loenen, who researched the parental support provision towards children with a physical disability. She presents her study in the thesis: ‘Parental support for children and adolescents with a physical impairment in northern Tanzania.’

## Theoretical Background

As mentioned earlier, disability is more than just a biomedical condition; it can cause and can be caused by social mechanisms, like poverty and exclusion. A disability, both physical and intellectual, is not merely the impairment, but rather a lack of (possibilities for) participation within the community (LF, 2014a) or limitations in human functioning (Mji, 2001). For a long time this social dimension has been ignored in literature on disability (Edgerton, 1984; Ginsburg & Rapp 2013; Kasnitz & Shuttleworth, 2001; Schuelka, 2013). The term ‘disability’ implies that the person is unable to participate in the community. It is seen as divergent from the norm. As norms are formulated by the local socio-cultural context, so is deviation and therefore what is considered a disability. According to Ginsburg and Rapp (2013) disability then should be seen in the context of social interactions.

### *Importance of parenting*

Having an impairment is often associated with having a pile-up of stressors which can have negative impact on the quality of life and wellbeing (Migerode, Maes, Buysse & Brondeel, 2012) and therefore can have a great influence on a person’s development as well.

Bronfenbrenner showed us that the development of a child consists of continuous interaction between the child and his/her (social) environment (Gardiner & Kosmitzki, 2005). His ecological model shows that different, but intertwined systems influence the development of the child. The most direct of these systems is the microsystem, which exists of the interaction between the child and its immediate social context. Parent-child interaction is one the most prominent microsystems (Eldering, 2008; Gardiner & Kosmitzki, 2005). Parents are the ones conveying (cultural) norms, helping to develop self-esteem and self-concept, providing security, etc. (Gardiner & Kosmitzki, 2005). So, the relationship between the child and its parents is of key importance in the life and development of any child (Ansell 2005), but even more so in that of children with an intellectual disability. Research shows that persons with an intellectual impairment have relatively small social networks, consisting primarily of close family members and professionals, and therefore rely mainly on their parents for social support (Alotaibi, 1997; Lippold & Burns, 2009).

One of the mechanisms which make up the parent-child interaction, is social support. According to Alotaibi (1997) Lippold and Burns (2009) and Migerode et al. (2012) social support is especially beneficial to persons with a(n) (intellectual) disability. It affects their quality of life by developing self-awareness, self-esteem and coping skills (Alotaibi, 1997; Lippold & Burns, 2009; Migerode et al., 2012).

### *What is social support?*

Cobb’s (1976) popular definition states that social support is an attempt to make a person feel cared for, loved, esteemed and valued, as well as giving a person a sense of belonging to a social network (Chen, Kim, Mojaverian & Morling, 2011; Kerres Malecki & Kilpatrick Demaray, 2002; Taylor et al. 2004). Chen

et al. (2012), Kerres Malecki and Kilpatrick Demaray (2002) and Nurrulah (2012) specify that social support consists of social transactions that are perceived as supportive by recipient and provider and which assist the recipient with coping with daily life and/or negates negative outcomes. According to Thoits (1995) social support from others is an important factor in assisting a person *“to change the situation, to change the meaning of the situation, to change the emotional reaction to the situation, or to change all three.”* (Thoits 1986 in Moritsugu, Vera, Wong & Duffy 2014, p. 47).

Since Cobb’s often cited article from 1976 many researchers have demonstrated the positive effects of social support. Through social support and engaging in social relationships an individual is be more successful in life and overcome difficulties more easily (Lippold & Burns, 2009; Migerode et al., 2012; Moritsugu et al., 2014; Taylor et al., 2004; Thoits, 1995). Social support is known to enhance the wellbeing (Cohen & Wills, 1985; Lippold & Burns, 2009; Migerode et al., 2012; Slevin et al., 1996; Taylor et al. 2004; Thoits 1995), speen recovery of health and reduce illnesses (Nurrulah, 2012; Taylor et al., 2004). According to Kerres Malecki & Kilpatrick Demaray (2002) in particular high risk or disadvantaged children profit from the presence of social support. Wenz-Gross and Siperstein (1997) argue that social support can protect children with learning difficulties from depressions. They show that children, who turn to people from within the home for social support, are less likely to be affected by negative classroom environments or peer-relationships.

Social support can be split into informational support, practical support, material support and emotional support . These forms of support often co-exist. Different actors can provide different kinds of support. Emotional support is a way to make the person more resilient, whereas informational, practical and material support are more problem focused. They are meant to help the recipient reappraise the stressor or to solve the problem. Therefore I will categorize social support into problem- and emotion-focused support.

### ***Problem-focused support***

The way in which a person responds to a certain situation, like having an impairment, depends on the way it is evaluated (or appraised) by the individual and his/her coping skills. When a situation is perceived as a threat or problem and the person does not have an appropriate response, a stress reaction can occur. Providing the individual with problem-focused support may help the recipient to redefine the situation as less threatening en thereby prevents negative reactions (Cohen & McKay, 1984; Taylor et al., 2004). This problem-focused support is subdivided into information, practical and material support.

The first is defined as providing advice or information that helps an individual to better understand and cope with a stressful situation. Here, the support provider teaches the recipient either on how (not) to respond to a certain situation or on the non-threatening nature of it (Cohen & McKay, 1984). Practical support includes assistance with daily hassles, like transportation, personal hygiene or homework (Wills & Cleary in Gottlieb & Bergen, 2010). Material support means tangible assistance. This includes financial aid or the provision of other specific goods (Taylor et al., 2004).

### ***Emotion-focused support***

Where problem-focused support aims at improving someone's evaluation of an external stimulus, emotional support is intended to improve a person's appraisal of the self. It is meant to make the person feel cared for, loved, esteemed and valued. It is presumed to provide the individual with a reserve of resources with which one is better protected against emotional losses caused by a certain situation (e.g. the loss of self-esteem or a gained feeling of inadequacy) (Chen et al., 2012; Cohen & McKay, 1984; Taylor et al., 2004).

According to Slevin et al. (1996) emotional support can be viewed as physical presence, empathy, expressed concern, affection, acceptance, understanding, love/concern, reassurance, encouragement and closeness with another person in whom the recipient can confide. Cohen and Wills (1985 in Chen et al., 2012) describe emotional support as either physical or verbal attempts to comfort another individual.

### ***Why provide social support?***

A lot of research is done concerning the motivations behind support provision and parenting. In the next section I will provide an overview of some of the factors known to be involved in the practice of social support.

Parent-child interactions do not exist in a vacuum. Both Bronfenbrenner's ecological model and Super and Harkness' developmental niche theory show that the parental beliefs and practices are shaped by the social and cultural contexts (Eldering, 2008; Gardiner & Kosmitzki, 2005). These social and cultural contexts create norms, values and meanings to relationships and therefore influence the motivations underlying parenting and support provision and utilization.

In independent cultures, for example, social support is often utilized in order to achieve one's personal goals or overcome one's problems. In more interdependent cultures, however, an individual utilizes support merely as a way to seek for consensus and compromises with others and aims at bringing harmony into the group. Therefore it is suggested that it is less likely for a person from a interdependent culture to explicitly use his/her social support network in response to a potential threatening situation (Taylor et al., 2004).

Chen et al. (2012) argue that problem-solving support can be rendered intrusive within independent cultures, where people are encouraged to be autonomous individuals. On the other hand in more collectivist cultures people are more concerned about maintaining interdependent relationships and therefore are more accepting towards receiving any kind of assistance. Also, in certain cultures people are known to be more hesitant in providing emotional support, since that deviates from the hegemonic social norms. In these, often more collectivist cultures reinforcing one's self-esteem is rendered a less important motivation of support than is strengthening relational ties. Besides this, however, the overall goal of support, namely making someone feel valued and esteemed and giving them a sense of belonging, is the same across cultures (Chen et al., 2012; Taylor et al., 2004).



Diken (2012) states that socio-cultural factors, like beliefs, religion, stigma and politics, are key determinants in the way a disability is interpreted and experienced. In societies with a low education level, like Tanzania, these socio-cultural aspects are known to be important explanations of attitudes towards the disability and the disabled.

Negative attitudes may result in low expectations of the child's capabilities, which in turn might reduce the eagerness of the parent(s) to encourage and support the child (Bywaters, Ali, Fazil, Wallace & Singh, 2003).

So, cultural norms define the valuation and expectations parents have of their child. In African cultures, for example, children are primarily seen as a continuation of the familial lineage and contributors to the family's welfare. They are expected to provide the needs for the elder generation(s), either immediately or in the long term. The child, then, is valued according to the likelihood of him/her realizing these expectations. This will depend on the child's characteristics, like gender, place in birth order or health. Girls or children with a severe disability, for example, are seen as less likely to perpetuate the family name and therefore more at risk of neglect or abuse. After all, the valuation of the child influences the support a parent gives to the child (Ansell, 2005).

So, in the African context a child is often valued by the parent(s) according to his/her ability to reciprocate (Ansell, 2005; Lippold & Burns, 2009). According to Lippold and Burns (2009) having the skills to reciprocate is essential for building and maintaining social relationships and receiving social support; individuals prefer to have equal exchange of social resources, like support (Chen et al., 2012). This exchange of social support is considered in the long term, i.e. what one gives now (s)he expects to get in return in the future and vice versa (Antonucci, Fuhrer & Jackson, 1990). Parents care for the child expecting that later in their life the child will take care of them.

Children with an intellectual impairment are thought to be less able to live up to the reciprocal expectations, i.e. providing needs for the elder generation(s) in the future. Therefore, the parents' assessment of the child's capabilities might influence their willingness and efforts to provide social support (Chen et al., 2012).

Wenz-Gross and Siperstein (1997) argue that children with (severe) intellectual impairments have difficulties in interpreting supportive interactions and lack the ability to behave in a manner that evokes support from others. The same was found by Farmer and Farmer (1996 in Alotaibi, 1997), who argue that disabled students often show disruptive behavior which causes social isolation. So, one might argue that it is not just the valuation of the child's capabilities, but also the child's character (or a pile-up of both) that can affect support.

Both Heller, Hsieh & Rowitz (1997) and Kerres Malecki and Kilpatrick Demaray (2002) found that parental support depend also on the child's age. Parents evidently spend more time and show more support to younger children than older ones. An explanation for this is that giving care becomes easier and caregivers become more adjusted to their roles.

As mentioned earlier, other child characteristics are also involved in the valuation of the child and therefore the parent-child interaction. The child's gender, for example, is known to influence the support provision. Previous research shows, for instance, that fathers are more supportive towards their male child with a disability than toward a female child with a disability (Heller et al., 1997). However, Heller et al. (1997) found little impact of the child's gender on support.

Not just the child's gender can mediate social support provision, the gender of the parent can also affect the relationship. In Africa, women are traditionally the primary support providers to their children (Mbwilo et al., 2010). In families of children with a(n) (intellectual) disability this seems to be particularly true (Heller et al., 1997; Mbwilo et al., 2010). Research points out that mothers spend more time with their children (Heller et al., 1997) and provide most types of support (Hartley, Ojwang, Baguwemu, Ddamulira & Chavuta, 2004; Heller et al., 1997; Mbwilo et al., 2010; Pelchat, Lefebvre & Perreault, 2003). Fathers, on the other hand, provide a bit more financial support (Heller et al., 1997).

One explanation is that women are often socialized to play caring roles. Another hypothetical reason is that women have less competing and time consuming roles than their male counterparts and therefore have more time to spend on the child(ren). A third hypothesis says that women and men play "different but complementary tasks within the family." (Heller et al. 1997).

(Lack of) knowledge by the caregiver can also be an important determinant on how people experience disabilities. Parents may lack knowledge on how to provide appropriate care. For example, they might not have enough knowledge on how to play a mediation/facilitation role in fostering children's exploration and learning (Garcia et al., 2008). Also, there can be a lack of knowledge on prognosis and management of disabilities - especially intellectual disabilities (Njelesani et al., 2011).

### ***Current research***

This review of the literature teaches us that parental support towards the child or youngster with an intellectual disability is essential for his/her wellbeing. This support is categorized into problem-focused (aimed at reappraising or solving the problem) and emotion-focused (enhancing the sense of the self), the former being subdivided in informational, practical and material support. Several factors are known to be involved in the motivation of support provision. However, not much research on this subject is done in the African context, nor is there much known about the support provision towards children with an intellectual disability. Therefore this research will try to answer the following questions: 'In what ways do parents support their children with an intellectual impairment in North Tanzania? And what motivates or limits this support provision?'

## Current Study

### Methods

To answer the main question three organizations which are sponsored by the Liliane Foundation, were visited in three different districts in northern Tanzania, i.e. Moshi, Sengerema and Musoma. In each of these places semi-structured interviews were conducted with children with an intellectual impairment ( $n=14$ ), their present parent(s) ( $n=16$ ) and professionals ( $n=12$ ). Based on the literature the two types of social support were surveyed: problem-focused and emotion-focused support. The first was then subcategorized into informational (grant information or advice on how to deal with the disability), practical (providing assistance with daily issues, split into 'bathing/washing', 'getting dressed', 'preparing food', 'eating food', 'transportation/going to school' and 'doing homework') and material support (providing basic and school needs). Emotion-focused support was subdivided into companionship, sharing, comfort and conflict. These themes were used to structure the interview (see Appendix I for an overview of these topics). After some testing and discussions with the key informant, the above mentioned topics were used during the interviews in order to get the appropriate information. In this way we wanted to find out what kind of support was given in what manner. With follow-up questions we investigated the reasons and motivation behind it. Also, pictures were used to visualize some of the topics (see Figure 1 and Appendix II).



Figure 1: Examples of pictures used to visualize 'practical support'.

In total 33 parents (21 mothers, 12 fathers) were interviewed, of which 16 (11 mothers, 5 fathers) had a child with an intellectual disability. When there were two caregivers to one child, they were interviewed separately from one another, in order to give them the freedom to give their unique outlook on the situation. To triangulate the parental accounts we also talked to their children and professionals. The professionals were either mediators for the Liliane Foundation, teachers or other persons who worked closely with the children and were familiar with their home situation. Table 1 shows the distribution of the informants.

The children were between the ages 9 and 21 and had either an intellectual impairment (I.I.) ( $n=14$ ) or a physical impairment (P.I.) ( $n=12$ ). The latter were included as a control group. The children were chosen at random, with the age, type of impairment and presence of at least one parent as only requirements. The youngsters and their parents were selected and approached by the mediators. The interviews were conducted in private places familiar to the respondent, either at home or the mediator's office, again to increase their sense of freedom and comfort.

**Table 1: Schematic overview of the distribution and categorization of the respondents.**

	<b>Total number of children</b>	<b>Number of children with an I.I.</b>	<b>Total number of parents</b>	<b>Number of parents with a child with an I.I.</b>	<b>Total number of professionals</b>
<b>Moshi</b>	10	5	13	6	4
<b>Sengerema</b>	9	5	13	6	4
<b>Musoma</b>	7	4	7	4	4
<b>Total</b>	26*	14	33	16	12

*\* Children who had both a physical and an intellectual impairment, were classified as "child with an I.I."*

Before conducting the interviews the respondents filled out a consent form (see Appendix III), stating their agreement with the use of their information for this research. By using a semi-structured interview with every informant individually, rather than, for example, focus groups or questionnaires, we ensured that the informant would feel free to answer the questions open- and honestly. We made sure to give him/her room to propose his/her own perception on the situation.

#### Reliability and validity

While conducting the research we were faced with a number of challenges: first of all, a language barrier was present between the researchers and participants, since none of the investigators were familiar with the local languages and many of the informants did not speak English (well). In addition to this, the researchers were not well acquainted with the cultural contexts, which jeopardizes an accurate understanding and interpretation of the accounts. We also could not prevent people from knowing we were foreigners, associated with one of their (indirect) donors; since we attempted to search for behaviors within parent-child relationships by using peoples accounts on it, this poses the threat of social desirability in the answers of the respondents, especially those of the parents. Lastly, interviewing children with an

intellectual impairment proved to be problematic; some of the children turned out to be incapable of understanding and answering the questions accurately, leading to some incomplete accounts.

We tried to overcome these difficulties by utilizing key informants (mediators from the Liliane Foundation) in all three visited areas. They were familiar with the other informants, the cultural context and the subjects discussed. Their presence helped to give the children and their parents a sense of security, which made it easier for them to open up to us. The key informants served as language interpreter during the interviews with the children and parents. However, most of them were not fluent in English either, which meant that sometimes questions and answers might be incorrectly translated. By asking follow-up question we attempted to solve this problem. Because the mediators were well integrated into the local context, they functioned as ethnographic interpreters; they helped us to understand and interpret the participant's accounts accordingly. Prior to the data collection the topics and visual aids were discussed with the mediators to come to an agreement on their meaning. One of the pictures we initially wanted to use, for example, depicted a child using knife and fork for eating. After consulting our key informant this turned out to be an unusual sight for Tanzanians, since they usually eat with their hands. Therefore an image was used, which was more relatable to the participants.

Another technique we used to enhance the reliability is triangulation. Since it is known that people have a tendency to answer questions about their own experiences or views according to social norms, or in such a way that they believe are socially acceptable or desirable, it might be beneficial to get an outsider's perspective on the matter. By using multiple sources reflecting on the same topics (in this case the problem-focused and emotion-focused support provision from parent(s) to their impaired child) we attempted to increase the trustworthiness of this research: besides asking the parents about certain situations (ratified by examples), their children and professionals were queried. This method proved to be useful, since professionals often provided a more nuanced insight than the parents. After asking whether or not children shared the feelings and thoughts of their parents, for example, all parents confirmed that they did. Professionals, however, had another opinion on the topic.

### Analysis

After the collection of the data the gained information was qualitatively analyzed by doing a content analysis on the informant's accounts. Because there did not seem to be any striking differences in the outcomes between the various areas, the analysis will be based on all three regions. Also, the sub domains of emotional support (companionship, sharing, comforting and conflict) were found to have such an overlay, that it will be analysed as a whole. Both the testimonies of the I.I. and the P.I. group will be evaluated. However, it turned out that in most themes both groups were indistinguishable and therefore there they will be analyzed together .

## **Results**

The visited cities of Moshi, Sengerema and Musoma are three of the more prosperous areas in Eastern Africa. Moshi lies at the foot of Mount Kilimanjaro and Sengerema and Musoma are located near Lake Victoria, making both of these regions convenient for agriculture, especially during the wet season. However, a large part of the population of northern Tanzania still lives in poverty, including the majority of the informants. The fertility rate is, like in most African countries, quite high; many families consist of five or six children. Although in former days there were many different local beliefs, nowadays the main religion in the area is Christianity (Catholic and Protestant-like theologies).

In 16 of the 26 interviewed families both parents were present, although not all of them were interviewed. In nine of the other cases the mother was the one caring for the child as a single parent. In four of these families the father left or was sent away by the mother. More than three quarters of the mothers and half of the fathers did not have a job at the moment of the interview. A majority of the respondents did go to school (77% went to primary school; 13% attended secondary school). About half of the parents considered themselves Roman Catholics, while the other half belonged to other Christian denominations. Only one parent said to be Muslim.

Out of the 26 children we interviewed, 14 children had an intellectual disability whether or not along with a physical impairment (I.I.) and 12 were suffering solely from a physical disability (P.I.).

### Informational support

Even though only five parents indicated that they had sufficient information about the disability, all claimed to provide their children with information regarding the impairment. Just three children contradicted this. Parents generally encouraged their children by telling them to do well at school or that they have to accept their impairment, since they cannot change the situation. A child said: *"She [mother] encourages me to do some activities and that God will help me."* Another one said *"I tell my mother I have a lot of difficulty with writing. She told me I have to work really hard because of my disability and I cannot change it."* Just two of the parents reported to inform their children about the nature of the impairment. As one of the professionals put it: *"They instruct, they don't communicate."*

### Practical support

Parents, as well as the children and professionals, seemed to agree that the practical care is primarily done by the mother. The only domains where fathers are equally or even more involved were 'transportation/going to school' and 'doing homework'. The latter might be explained by the fact that in general the men had a higher level of education.

### Material support

Half of the parents stated that they were not able to provide for their children's school needs, due to poverty. They did, however, try to provide the basic needs, like food and clothes.

The professionals presented some more interesting information regarding the material support parents give to their children. They say that many parents do have the resources, but do not want to spend it on the impaired offspring.

### Emotional support

Children with an intellectual impairment spend most time with their mother. Only three of them claimed to be spending the majority of their time with others. About half of the children with a physical disability, however, said that they spend most time with their sibling(s).

There also seemed to be a difference in the content of the togetherness: parents of both intellectually and physically impaired children, the children themselves and the professionals, all acknowledge that the children spend most time with their parent doing household jobs or garden work together. A teacher told us: *"In African culture women are to do domestic work, while men are working outside. So when a child is with the mother, most things they do together are activities that women do."* However, parents of physically challenged children claimed to talk about school matters, life and the child's future, whereas mothers and fathers of intellectually impaired children were mainly concerned with storytelling or talking about house work. This difference is even more evident when you look at the children's accounts.

Almost all of the parents of children with a physical impairment indicated that they played with their child regularly, while parents of children with an intellectual impairment often did not have fun with their child at all.

Even though nearly all parents (only five told us otherwise) claimed that the child shared his thoughts and feelings with the them, professionals seem to have another opinion on the matter. They said that there seems to be a communication barrier between most parents and their (severely) intellectually disabled child. Some of the comments:

*"Some share, others cannot share because they are not able. For example, because they are too young, or the condition of their disability is too severe. Then he or she doesn't know what is wrong with him/her."*

*"Yes, those that have a moderate disability can talk to the parents. But those with a more severe impairment, they forget for a short time, so they can't talk to their parents."*

*"Children with physical impairments can express themselves easily and parents can understand them. While children with intellectual impairments cannot, so parents don't know how they feel or what they want to do."*

Another important difference in support between children with an intellectual and a physical impairment is the way the parents handle a conflict. Intellectually impaired children reported to be punished more by beating than children with a physical impairment. Parents and professionals stated the same thing, although parents claimed to use physical punishment only as a last resort. One father told us: *“If I tell him more than once, the third time I must punish him, so he doesn’t make the same mistake. So, like, people like [name child] if you don’t stop him, he can do worse.”* He explained that because of the low level of understanding from his son, sometimes physical pain can be the only way to reach him and teach him how to behave. Several other respondents gave similar accounts. Other parents claimed to punish their child more gentle than other children because *“he doesn’t know what he is doing wrong”*.

#### What motivates or limits the support provision?

It did become clear that, according to the informants, the community often holds a negative attitude toward (people with) disabilities; some parents declared that people misuse or devalue their intellectually disabled child and his/her family as a result of traditional beliefs. Both parents and professionals attribute these attitudes to the fact that the community believes the child is a curse. They believe that the child is a punishment from God, gods or ancestors for mistakes in the family’s past. However, both parents and professionals see a shift towards a more accepting attitude, due to an increase in education, visibility of successful persons with a disability and the disappearance of traditional beliefs. A number of professionals stated that not just community members, but also some parents (in particular fathers) see the child as a curse and therefore neglect the child. In northern Tanzania mainly mothers of children with an intellectual disability are blamed for the impairment, causing some fathers to abandon or neglect the family and the community to isolate them, leading mothers to take care of the child all by herself.

On the other hand, culture, beliefs and customs were mentioned as motivations for support as well. It is believed, for example, that taking care of the disabled protects you from bad things. One of the professionals said: *“You know, as an African, if you are not taking care, they will get something very bad. So they just do that [i.e. assisting the child], because they believe that when you are not taking care of the disabled, God will give you something bad”*. Parents stated that they considered the disability to be given by God, making it their duty to care for the child.

This aspect of belief was also evident in the way parents taught their child about the disability. A number of parents stated that they explained the child their impairment was god-given and therefore should be accepted as an unchangeable fact.

Advising the child on how to overcome the problem seemed to be the main concern of the parents; few seemed to be concerned with enhancing the child’s self-esteem or making him/her feel valued. Only one



parents stated he wanted to make the child feel loved, by showing his affection. According to the professionals this can be accounted for by the fact that showing emotional support is not part of the African culture. According to their customs, interaction between the child and his/her parents, for example, is more likely to exist of work-related activities (doing chores in the house or garden work) than of play or showing affection. Professionals told us that talking about one's feelings or thoughts is not common in African culture. One mediator, for example, stated that: *"Even children without a disability will not go to their parents to express their feelings, because that is not our culture. They just resist to talk."*

As mentioned before, mothers are usually the ones taking care of the child. They are more involved in all types of support, including material support. The parents, especially those of intellectually impaired children, indicated that the practical care within the home, like 'assistance with washing' or 'preparing food', is the mother's responsibility. The informants stated that this difference in support provision between men and women is due to the fact that fathers spend less time with the child. Often they are away during most of the day doing other activities outside of the home: *"Most of the time mother is at home, so she is very close to [name child]. I am away most of the time to get things for the family. When I am around I do assist him, but otherwise mother does the work."* According to eight parents and 12 professionals this is the result of the tradition gender pattern: *"In the African context parents have different duties."* In the northern Tanzanian culture a man is supposed to spend his time making a living elsewhere, while the mother stays at home taking care of the children and household.

Only one professional did not mention a (lack of) knowledge or education as a limitation or motivation for support. Professionals, for example, were concerned about the information provision, both toward the parent as well as from the parent towards the child. They said that many parents do not receive enough information themselves and therefore are not capable of giving the proper information to their child: *"Those with education talk about the disability with their children, but those without education know nothing, so they can't talk about anything."* The professionals stated that some parents are often not aware of the child's needs or capacities and are therefore unable to care for the child appropriately. Because parents do not render their intellectually impaired child capable to provide for him/herself or the family, they often do not want to spend time or resources on the child.

The professionals told us that, besides poverty, a reluctance to spend (financial) resources prevents parents to provide for the child's needs. They claimed that some parents, who do have the (financial) resources, do not want to 'waste' these on their impaired offspring. Some of the comments:

*"Some parents didn't do it [i.e. providing the child with school needs], they support more for the normal children. Because they know other parents are looking at the disability and these children can't help anything. They cannot give back."*

*“The main reason is that they don’t value their children, especially children with disabilities.”*

*“Some have money, but don’t see a CWD as being able to contribute [...] They do pay the school fees for the other children, but not for the one with disabilities.”*

*“They think it is a waste of money to spend it on a disabled child. This is very evident, even if you go to the communities you find the disabled children at home while those that are not disabled, are in schools. This is just because of poor perceptions towards people with disabilities.”*

In addition to this, professionals argued that parents are not able or not willing to invest their time in the impaired offspring. Two of them attribute this to poverty; like the parents, they say that both mothers and fathers are often required to spend most of the day outside the home looking for family needs, due to poverty. Three of other professionals, however, stated that a negative attitude towards the disability prevents parents to spend time with their child. As one of them told us: *“Fathers have no time for disabled children. They see it as wasting their time”*. Parents care for the child expecting that later in their life the child will take care of them. Since they do not think their impaired child is capable of this, they will not waste their time and resources on that child. They said that it is particularly evident for children with an intellectual impairment.

Seven parents of intellectually impaired children expressed (great) concern about their child’s abilities to be self-sustainable in the future. Professionals told us that educating the parents about the child’s abilities, for example by bringing them into contact with successful impaired adults, will show them their child’s possibilities and therefore might be beneficial for the support provision to the child. Parents need to know that their child is capable of becoming a self-sustaining grown-up in order for them to be willing to invest in the youngster’s development.

The (perceptions of the) child’s abilities, whether or not resulting from the impairment, do not only affect the willingness to invest time and money on the child; it also influences other aspects of support, like conflict and sharing thoughts and feelings. Parents claim to punish their intellectually impaired child more gently or more physically than children with only physical challenges, because they believe the child has a low level of understanding. Professionals claimed that children with an intellectual disability often do not share their emotions, because they might struggle with expressing themselves or parents might simply misinterpret or misunderstand the child’s intentions.

I have not found any differences between other child characteristics, like the way boys and girls are treated, nor have I found any striking diversities in age groups.

## Conclusion

This research focused on the determinant factors involved with parental support towards children with an intellectual disability. Literature shows that social support is important in a person's wellbeing and health, especially for individuals facing a high number of stressors, like people with an impairment. In particular children with an intellectual disability are known to have small support groups and depend primarily on their parents. Social support is categorized into problem-focused (providing advice and concrete assistance) and emotion-focused (making the receiver feel loved and valued in order to enhance his/her self-esteem), the former being subdivided in informational, practical and material support. In the present study 14 children with an intellectual and 12 with a physical impairment, their parents and professionals were interviewed in three places in northern Tanzania. By asking questions about the respondent's experiences and thoughts on the matter I wanted to find out in what ways the parents supported their child and what were the motivations behind it.

It can be concluded that the parents in this research are mainly involved in providing problem-focused support. They help the child to overcome the problems associated with having an intellectual impairment, by assisting him/her with becoming a self-sustaining grown-up. The time they spend with their child, exists of performing house or garden work or encouragement for school. The parents seemed less concerned with showing affection or making the child feel loved or cared for. This can be accounted for by the fact that children are valued according to the cultural norms; within the African tradition children are expected to reciprocate their parents' efforts by caring for them in the future. This might explain why parents are so concerned with making sure that the child is able to be self-sustainable as a grown-up. If parents believe the child is not capable of this reciprocation they are less willing to invest time and resources in the child's development. Therefore, the appraisal of the child's capabilities and the subsequent future perspectives are determining for (a lack of) parental support provision.

Next to this appraisal of the child's abilities to reciprocate, there are other ways in which the cultural context influences the social support provision. Local customs and beliefs create the norms concerning how disabilities and impaired persons are experienced or viewed. As was evident from a previous study by Mbwilo et al. (2010) some people in Tanzania believe that intellectual disabilities are a curse from God, gods or ancestors. In most cases the mother will be blamed for this, resulting in the fact that some fathers neglect the child or leave the family, leaving the mother to take care of the children by herself. However, as this and previous studies (Hartley et al., 2004; Heller et al., 1997; Mbwilo et al., 2010; Pelchat et al., 2003) suggest, mothers seem to be more involved in most types of support, even if both parents are present. As is customary in East-African culture, the man is responsible for the provision of money, while the woman remains at home, taking care of the children and the household. According to research by Heller et al. (1997) the father is the primary source of financial provision to the family. However, this current study did

not find such paternal involvement in material support. This might be explained by the fact that most informant lived in poverty or the father was absent.

Unfortunately, there were some threats to the reliability of this research. The language and culture barrier, for example, and potential social desirability of the answers might have influenced the results. However, we have tried to enhance this study's reliability by employing interpreters who were familiar with the families and the social and cultural contexts, and by interviewing different sources, i.e. parents, their children and professionals. By using this triangulation method we tried to receive additional information from different perspectives.

## Discussion

This research shows that the cultural norm and valuation of the child's abilities and future are important factors in parental support towards children with an intellectual disability in northern Tanzania. They influence the time and resources spent on the child, the kind of support provided and who the support provides. The cultural context and the way parent value the child are interrelated, since the cultural contexts create the norms which are involved with the creation of expectations and goals. These expectations and goals influence the way parents assess the child's possibilities, and thereby affect their support provision. Like Ansell (2005) argued, reciprocity is an important aspect of parent-child relationships in the east-African context. This means that parents expect that, later in life, the child pays back the efforts the parent put into the child's upbringing. When the parent believes their offspring is not able to live up to these expectations, for example because the mental abilities of the child are not rendered sufficient, they are less likely to invest time and resources in the child's development. Although much literature is written about the effects of child's characteristics on social support provision, the concept of reciprocity and the appraisal of the child's abilities remains underexposed. Since organizations, like the Liliane Foundation (2014a), are often concerned with making the social environment (including the family) more accommodating in order to include children with a disability, this might be an interesting theme to address in relevant policies. It is therefore recommended that attention will be given to educating parents about the child's abilities and future perspectives, in order to improve the parent-child relationship.

One method mentioned by several participants of this study, is showing examples of successful impaired adults. By making the parents aware of the fact that their child can become a successful, self-sustaining individual, who is able to reciprocate despite their impairment, they might realize their child's potential. Some of the special and inclusive schools visited during the research period had one or more impaired teachers or other staff members. They did not only function as role models for the children themselves, they also could be seen as examples for the parents. I would suggest making these well functioning grown-ups more visible to parents and community members alike. Hopefully, this can help to improve their valuation and expectations of the child and therefore their attitudes towards the disabled youngsters. We cannot (and should not) alter the cultural norms, but it might be possible to make the social environment of children with an intellectual disability in northern Tanzania more aware of their possibilities.

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# Appendix I - Topic Lists for Semi-Structured Interviews

## a) Topic list for interview with child/youngster

Code	Subject	Example question
<b>GENERAL</b>		
G1	Name	
G2	Gender	
G3	Age	
G3	Education	
G5	Number of siblings	
G6	Living situation	
<b>INSTRUMENTAL SUPPORT</b>		
I1	Informational	Who do you talk to about your disability? - If caregiver: how does he/she react? Can you give an example? - If someone else: why not caregiver?
I2	Practical	Here are some pictures* of daily things. Can you point out what things you can do yourself and what you need help with? a) If “need help”: Who helps you with it? - If parent: How does he/she help you? - If someone else: Why not your caregiver(s)?
I3	Material	Who provides you with schoolbooks and school fees? - If not parent: Why not your parent(s)? Who provides you with food and clothes? - If not parent: Why not your parent(s)?
<b>EMOTIONAL SUPPORT</b>		
E1	Companionship	With whom do you spend most of your time?  What do you do together? a) Do you talk together? - If yes, what about? Can you give an example? - If no, why not? b) Do you play/laugh/joke together? - If yes, can you give an example? - If no, why not?
E2	Comforting	What makes you sad? Can you give an example of that?  When that happened, did you share this with your parent? - If no, why not? - If yes, how did he/she react? Did that make you feel better? - If no, why not? What do you think would help?
E3	Sharing	What makes you happy/proud? Can you give an example of that? When that happened, did you share this with your parent? - If no, why not? - If yes, how did he/she react?
E3	Conflict	How did you feel about that? Is your caregiver ever mad or upset at you? Can you give an example? What happened? How did that make you feel? In general, do you like spending time with your caregiver(s)? - Is there anything you would like to change about the relationship?
<b>OPTIONAL</b>		
O1	Past	What was the situation like when your father/mother/parents were still alive/around?
O2	Future	How do you see your future? What do you want to be when you grow up? How do your parents support that?

\* Here pictures were used to guide the question. See Appendix II.

**b) Topic list for interview with caregiver**

Code	Subject	Example question
<b>GENERAL QUESTIONS</b>		
G1	Name	
G2	Gender	
G3	Age	
G3	Education	
G5	Occupation	
G6	Religion	
G7	Number of children	
G8	Marital status	
G9	School child	
<b>QUESTIONS ABOUT DISABILITY</b>		
D1		Can you describe your child's disability to us?
D2		What do you think caused the disability?
D3		When and how did you find that your child was different than other children? What did you do?
D3		How does the community respond to the disability?
<b>INSTRUMENTAL SUPPORT</b>		
I1	Informational	Do you feel like you have enough information about how to handle/live with the disability? Do you talk to your child about the disability?
I2	Practical	Here are some pictures* of daily things. Can you point out or make piles which things he/she can do by herself and what things he/she needs help with? a) If "needs help": Who helps him/her? - If someone else: Why don't you help? - If caregiver: How do you help him/her?
I3	Material	Who provides the child with schoolbooks and school fees? - If someone else: Why don't you help? Who provides the child with food and clothes? - If someone else: Why don't you help?
<b>EMOTIONAL SUPPORT</b>		
E1	Companionship	How much time do you spend with your child? What do you do together? a) Do you talk together? - If yes, what about? Can you give an example? - If no, why not? b) Do you play/laugh/joke together? - If yes, can you give an example? - If no, why not?
E3	General	Can you describe your child's character?
E3	Comforting	What makes your child sad? Can you give an example of that? When that happened, what did you do? Did it help? - If no, why not? What do you think would help?
E5	Sharing	Does your child share with you when he/she is happy/sad? Can you give an example of that? When that happened, what did you do?
E6	Conflict	Are you ever mad or upset at him/her? Can you give an example? When that happened, what did you do?
E7	General	In general, are you satisfied with the relationship you have with the child? Do you think he/she knows that? - If yes, how do you show? - If no, what do you think should change to improve the relationship?
<b>OPTIONAL</b>		
O1	Other parent	What was the situation like when other parent was still alive/around? [When both around: How is the relationship between other parent and child?]
O2	Future	How do you see the future of your child?

\* Here pictures were used to guide the question. See Appendix II.

**c) Topic list for interview with professionals**

Code	Subject	Example question
<b>GENERAL</b>		
G1	<i>Job</i>	
G2	<i>Organization</i>	
G3	<i>Employment</i>	How long have you been working here?
G3	<i>Contact</i>	How much contact do you have with children with disabilities and their parents?
G5	<i>Caregiver</i>	In general, who are the main caregivers of children (at home)?
G6	<i>General support</i>	In what ways do parents support their children with disabilities?
<b>INFORMATIONAL</b>		
I1	<i>What's going on</i>	a) Do you feel like parents have enough knowledge about the child's disability? b) Do parents have a place/people to go to when they have questions about the disability? c) Do they talk about it with their children? (How? Example?)
I2	<i>Supporting factors</i>	What, do you think, would improve the information provision of the parent to the child?
I3	<i>Limiting factors</i>	What do you think could be the reason why parents wouldn't talk to their children about their disability?
I3	<i>Mental vs. phys.</i>	Is there a difference in the information provision from parent to child with mental or physical disabilities?
<b>PRACTICAL</b>		
P1	<i>What's going on</i>	In general, who helps the child most with practical things, like getting dressed, eating, moving around etc.? (How? Example?)
P2	<i>Supporting factors</i>	Why, do you think, some parents do provide practical support to their child?
P3	<i>Limiting factors</i>	Why, do you think, some parents don't provide practical support to their child?
P3	<i>Mental vs. phys.</i>	Is there a difference in the practical support provision from parent to child with mental or physical disabilities?
<b>MATERIAL</b>		
M1	<i>What's going on</i>	a) In general, who provides the child with school needs? b) In general, who provides the child with basic needs, like food and clothes?
M2	<i>Supporting factors</i>	What do you think would improve the material support?
M3	<i>Limiting factors</i>	If a parent doesn't provide the child with fees etc. why is that?
M3	<i>Mental vs. phys.</i>	Is there a difference in the material support provision from parent to child with mental or physical disabilities?
<b>EMOTIONAL SUPPORT (COMPANIONSHIP)</b>		
C1	<i>What's going on</i>	a) With who do CWD spend most of their time? b) What do they do together?
C2	<i>Supporting factors</i>	What do you think would improve this?
C3	<i>Limiting factors</i>	What do you think can be a reason why a parent doesn't spend time with the child?
C3	<i>Mental vs. phys.</i>	Is there a difference in the companionship of parents and children with mental or physical disabilities?
<b>EMOTIONAL SUPPORT (SHARING)</b>		
S1	<i>What's going on</i>	Do you think children feel comfortable sharing things/feelings with their parent/guardian?
S2	<i>Supporting factors</i>	Why, do you think, some children do share things/feelings with their parent/guardian?
S3	<i>Limiting factors</i>	Why, do you think, some children don't share things/feelings with their parent/guardian?
S3	<i>Mental vs. phys.</i>	Is there a difference in the sharing of things/feelings between children with mental and physical disabilities?
<b>EMOTIONAL SUPPORT (COMFORT)</b>		
CF1	<i>What's going on</i>	How do most parents react when their child is sad or upset?
CF2	<i>Supporting factors</i>	What do you think could be a reason for parents to comfort their child when he/she is sad or upset?
CF3	<i>Limiting factors</i>	What do you think could be a reason why parents don't comfort their child when he/she is sad or upset?
CF3	<i>Mental vs. phys.</i>	Is there a difference in the support provision from parent to children with mental or physical disabilities?
<b>EMOTIONAL SUPPORT (CONFLICT)</b>		
CN 1	<i>What's going on</i>	What do parents do when they are upset/angry/mad at the child?
CN 2	<i>Supporting factors</i>	
CN 3	<i>Limiting factors</i>	Why, do you think, do parents punish their children that way?
CN 3	<i>Mental vs. phys.</i>	Is there a difference in the way parent punish the child with mental or physical disabilities?
<b>OTHER</b>		
O1	<i>Dis. vs. non-disabled</i>	Do you think parents behave differently to their child with a disability than to a 'normal' child?
O2	<i>Mother vs. father</i>	Is there difference between the support provision by the mother and the father?
O3	<i>Girl vs. boy</i>	Is there a difference in the way parents support a girl vs. boy?

## Appendix II – Pictures used in the Interviews



**Getting dressed – Self**



**Getting dressed – Help**



**Washing up – Self**



**Washing up – Help**



**Going to school – Self**



**Going to school – Help**



**Preparing food – Self**



**Preparing food – Help**



**Eating – Self**



**Eating - Help**



**Doing homework – Self**



**Doing homework – Help**

\* In the original pictures both English and Kiswahili texts were used.

## Appendix III – Consent Forms

### Fomu ya ukubali / Consent form

Mtoto / Child

Tunaweza kutumia hii taarifa yako ya maelezo kwa matumizi ya chuo kwa kujifunza zaidi (watu wengine wanaweza pia kusoma). Je hili shirika linalowasaidia wanaweza pia kutumia kwa shughuli zake. Kwenye hii huu utafiti hatutaja jina

*We may use the reporting of your stories for our University thesis (may be consulted by others) and internal use for the Liliane Foundation. In the thesis the data will be anonymized.*

Jina la mtoto / Name child: \_\_\_\_\_

Jina la anayemtunza / Name caregiver: \_\_\_\_\_

Tarehe / Date: \_\_\_\_\_

Mahali anapoishi / Place: \_\_\_\_\_

Wewe / Do you...:

- |  |  |  |
|--|--|--|
| • unaturuhusu kutumia maelezo yako kwa utafiti<br><i>consent to us using your story for research</i>                           | Ndiyo <input type="checkbox"/><br><i>Yes</i> | Hapana <input type="checkbox"/><br><i>No</i> |
| • ruhusa ya mzazi au anayemtunza<br><i>consent given by parent or by caregiver</i>   | Ndiyo <input type="checkbox"/><br><i>Yes</i> | Hapana <input type="checkbox"/><br><i>No</i> |
| • unaturuhusu kutumia jina lako kwa matumizi ya utafiti *<br><i>consent to us using your name for internal use*</i>            | Ndiyo <input type="checkbox"/><br><i>Yes</i> | Hapana <input type="checkbox"/><br><i>No</i> |
| • ruhusa ya mzazi au anayemtunza<br><i>consent given by parent or by caregiver</i>   | Ndiyo <input type="checkbox"/><br><i>Yes</i> | Hapana <input type="checkbox"/><br><i>No</i> |
| • unaturuhusu kurecodimaswali haya kwa matumizi ya utafiti*<br><i>consent to us recording this interview for internal use*</i> | Ndiyo <input type="checkbox"/><br><i>Yes</i> | Hapana <input type="checkbox"/><br><i>No</i> |
| • ruhusa ya mzazi au anayemtunza<br><i>consent given by parent or by caregiver</i>   | Ndiyo <input type="checkbox"/><br><i>Yes</i> | Hapana <input type="checkbox"/><br><i>No</i> |
| • unaturuhusu kutumia picha yako kwa matumizi ya utafiti*<br><i>consent to us using your photo for internal use*</i>           | Ndiyo <input type="checkbox"/><br><i>Yes</i> | Hapana <input type="checkbox"/><br><i>No</i> |
| • ruhusa ya mzazi au anayemtunza<br><i>consent given by parent or by caregiver</i>   | Ndiyo <input type="checkbox"/><br><i>Yes</i> | Hapana <input type="checkbox"/><br><i>No</i> |

\* Taarifa hii haitatangazwa kwa watu / This information will be published

Mimi mwenyewe kwa hiari nimekubali kujaza taarifa hii kama ilivyojieleza hapo juu na ninakubali kutoa ushirikiano kwa utafiti huu kwa undani.

*I hereby declare to have truthfully filled in the above stated information and agree on participation in this research as detailed in this document. .*

Kusaini au kutosaini / Sign or mark:

Mtoto / Child:

Anayemtunza / Caregiver:

\_\_\_\_\_

\_\_\_\_\_

**Fomu ya ukubali / Consent form**  
**Mtu mzima / Adult**

**Tunaweza kutumia hii taarifa yako ya maelezo kwa matumizi ya chuo kwa kujifunza zaidi (watu wengine wanaweza pia kusoma). Je hili shirika linalowasaidia wanaweza pia kutumia kwa shughuli zake. Kwenye hii huu utafiti hatutaja jina**

*We may use the reporting of your stories for our University thesis (may be consulted by others) and internal use for the Liliane Foundation. In the thesis the data will be anonymized.*

**Jina / Name:** \_\_\_\_\_

**Tarehe / Date:** \_\_\_\_\_

**Mahali anapoishi / Place:** \_\_\_\_\_

**Wewe / Do you...:**

- |   |   |   |
|---|---|---|
| • <b>unaturuhusu kutumia maelezo yako kwa utafiti</b><br><i>consent to us using your story for research</i>                           | <b>Ndiyo</b> <input type="checkbox"/><br><i>Yes</i> | <b>Hapana</b> <input type="checkbox"/><br><i>No</i> |
| • <b>unaturuhusu kutumia jina lako kwa matumizi ya utafiti *</b><br><i>consent to us using your name for internal use*</i>            | <b>Ndiyo</b> <input type="checkbox"/><br><i>Yes</i> | <b>Hapana</b> <input type="checkbox"/><br><i>No</i> |
| • <b>unaturuhusu kurecodimaswali haya kwa matumizi ya utafiti*</b><br><i>consent to us recording this interview for internal use*</i> | <b>Ndiyo</b> <input type="checkbox"/><br><i>Yes</i> | <b>Hapana</b> <input type="checkbox"/><br><i>No</i> |
| • <b>unaturuhusu kutumia picha yako kwa matumizi ya utafiti*</b><br><i>consent to us using your photo for internal use*</i>           | <b>Ndiyo</b> <input type="checkbox"/><br><i>Yes</i> | <b>Hapana</b> <input type="checkbox"/><br><i>No</i> |

\* **Taarifa hii haitatangazwa kwa watu / This information will be published**

**Mimi mwenyewe kwa hiari nimekubali kujaza taarifa hii kama ilivyojieleza hapo juu na ninakubali kutoa ushirikiano kwa utafiti huu kwa undani.**

*I hereby declare to have truthfully filled in the above stated information and agree on participation in this research as detailed in this document. .*

**Kusaini au kutosaini / Sign or mark:**

\_\_\_\_\_