



Parental support for children and adolescents with a physical impairment in northern Tanzania

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A qualitative study of provided support and the influence of social environment

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25-06-2015

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MASTER THESIS EDUCATION, SOCIALIZATION AND YOUTH POLICY

SPECIALIZATION EDUCATION, YOUTH AND INTERNATIONAL HUMANITARIAN COOPERATION AND AID

ACKNOWLEDGEMENTS

I carried out research on parental support in Tanzania in collaboration with the Liliane Foundation, as part of my Master 'Education, Socialization and Youth Policy' with a specialization in 'Education, Youth and International Cooperation and Humanitarian Aid' at the University of Utrecht.

The aim of the research is to describe what children, parents and local staff members experience to be determinants of parental support for children with physical impairments.

Completing my research would not have been possible without the help of some people that I would like to thank. First of all I would like to thank all my colleagues at the Liliane Foundation for the opportunity to work with them. I would like to direct special thanks to my supervisors, Anneke Hofs and Marije Koeman, for making it possible to carry out research in Tanzania and for their support, suggestions and feedback. I would also like to thank Makimi ter Beek, for providing us with valuable information on partner organizations in Tanzania and for facilitating our stay with the mediators.

I would like to express my gratitude towards the mediators from the local partner organizations of the Liliane Foundation in Tanzania: Sr. Ermelinda Mallya from Moshi, Alexander Maregesi from Sengerema and Dennis Maina from Musoma, for facilitating our stay and the warm welcome they have given us. I want to thank all of them for the time and effort they put into this research, for arranging meetings with participants and their patience in translating interviews, for sharing their stories and for making this an unforgettable experience.

Obviously, many thanks to all the children, parents and local staff members who shared their personal experiences. Last, but not least, I would like to thank Dr. Chris Baerveldt. Without his help and criticism I would never have completed this thesis.

Asante sana!

(Which means 'thank you very much' in Swahili, the official language in Tanzania)

Susan van Loenen

Abstract - The Liliane Foundation emphasizes the importance of parental support for children with impairments in underdeveloped countries. The aim of this study was to describe to which extent children and adolescents from 9 to 21 years old with a physical impairment in northern Tanzania received social support from their parents. Additionally, factors from parents' social environment that influenced the provided support were investigated. Data was collected through 36 semi-structured face-to-face interviews with children and their parents and twelve interviews with local staff members. For additional information open observations and informal talks were included. The discussed topics were based on the Network of Relationship Inventory (NRI; Furman & Buhrmester, 1985). The results showed that children received parental support to some degree. The types of support that were mentioned most, were material and emotional support. Furthermore, the factors from parents' social environment that influenced the provision of support were: information provision, poverty, lack of time, beliefs and culture, of which culture resulted to be of most influence. Many challenges are faced when it comes to the provision of parental support to physically impaired children in northern Tanzania. To reduce the negative effects of social environment, and to ensure improvements in parental support, recommendations are presented.

Keywords: Parental support; physical impairment; Tanzania; children; social environment

INTRODUCTION

At least 10% of the world's population lives with an impairment; the majority living in developing countries (World Health Organization, 2010). When it comes to children, one widely used estimate is that 93 million children live with a moderate or severe impairment of some kind (UNICEF, 2013). According to the World Health Organization, "The world's biggest killer and the greatest cause of ill health and suffering across the globe is extreme poverty" (WHO, 1995. In: Mji, Machlachlan, Melling-Williams & Gcaza, 2009). The Liliane Foundation is a Dutch non-governmental organization that aims to contribute to better future prospects for children and adolescents with an impairment who live in poverty, by ensuring that they are able to develop and use their talents, in order to participate equally in their families and communities. The foundation collaborates with local Partner Organizations in Africa, Asia and Latin America (Liliane Foundation, 2013, 2014).

In November 2009, the United Republic of Tanzania ratified the United Nations (UN) Convention on the Rights of People with Disabilities (CRPD) and its Optional Protocol (United Nations, 2010). Article 7 of the CRPD states that all necessary measures shall be taken to ensure that children with impairments fully enjoy all human rights and fundamental freedoms on an equal basis with other children. Having a positive parent-child relationship can have a positive effect on the development of children with impairments, like improved self-esteem, sense of self-worth and resilience (Liliane Foundation, 2014). The World Health Organization (2010) states that the relationships that these children and adolescents form with their peers and family are considered essential for personal growth

and development. Positive family relationships and support would nurture a safe and stable environment in which the child can grow up and develop. The WHO therefore argues that families as a whole should be considered key stakeholders in the rehabilitation process of the child. Families can be powerful agents of change towards inclusion, participation and expectations of the children with impairments, and can even affect the attitudes of the community (WHO 2010). The aim of the Liliane Foundation is to include families, in particular parents, during all stages of the rehabilitation process in order to promote the acceptance of the child (Liliane Foundation 2014). In order to examine to what extent parents are involved in their children's lives, and what types of support are provided by parents, research was carried out in northern Tanzania. Due to limitations and lack of time, not all types of impairments are included in this research. This study focuses on children and youngsters with a physical impairment. In addition, Den Uijl (2015, in preparation)¹ carried out a parallel study to investigate parental support for intellectually impaired children. The following research questions were formulated:

- In what ways do parents in northern Tanzania support their physically impaired children?
- What factors in parents' social environment determine the level of provided support?

¹Den Uijl, M. (2015). Parental support towards children and youngsters with an intellectual disability in northern Tanzania (Master thesis in preparation). Education, socialization and youth policy, Faculty of Social Sciences, University of Utrecht, Utrecht.

Impairment and social context

The value of children is a multidimensional concept. Besides the often discussed psychological value, it also has economical, socio-normative and religious aspects. The social and cultural context of where children live have a great influence on how they are raised and how they develop. In many non-Western societies, children are of different value to parents than in Western societies (Eldering 2006). Therefore, perspectives towards children with an impairment are most likely to differ from our European vision. Throughout sub-Saharan Africa, individuals with disabilities often face discrimination when they are not able to fully participate in the daily social and economic activities of the community (Stone-MacDonald 2012a, 2012b). The International Classification of Functioning, Disability and Health (ICF), developed by the WHO (2001), emphasizes the influence of environmental factors as well as personal factors to the activity and participation of people with impairments (Stucki, Cieza & Melvin, 2007). Figure 1 gives a representation of the ICF.

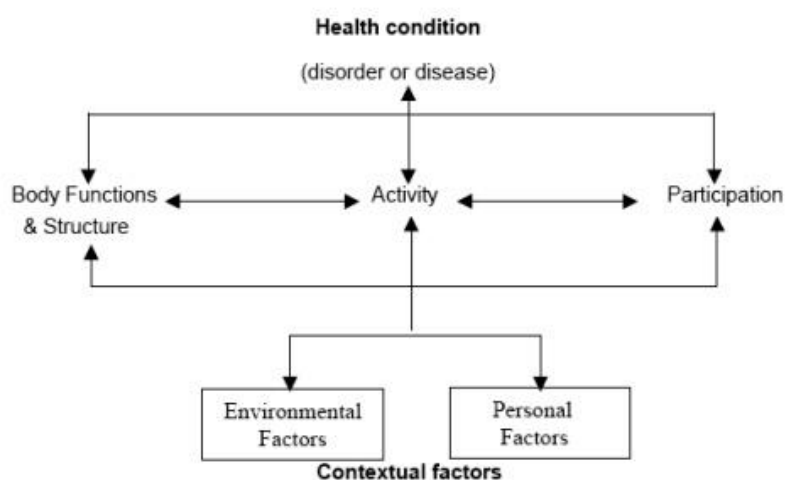


Figure 1. Representation of the International Classification of Functioning, Disability and Health.

The ICF defines impairment as problems in body function or alterations in body structure, for example: paralysis or blindness. Activity limitations are defined as difficulties in executing activities, like walking or eating; and participation restrictions are problems with involvement in any area of life, like facing discrimination in employment or transportation (WHO, 2011). In conclusion: Environment can play a limiting or facilitating role to the way people with impairments develop and function in everyday life. Due to several factors, children and adolescents with a physical impairment may experience environmental barriers to participation (Anaby et al., 2013; Piškur et al., 2012; Majnemer et al., 2014).

Having an impairment in Tanzania

According to Inclusion International, the 10% global prevalence of people with impairments actually translates to one in five of the world's poorest people (Inclusion International, as cited in Cameron, Nixon, Parnes & Pidsadny, 2005). As stated by the World Bank (2009), Tanzania has the highest rates of extreme poverty in the world, with 88.5% of the population subsisting on less than 1.25 dollars per day and 96.6% on less than 2 dollars per day. Poverty denies children their fundamental human rights and increases the likelihood of becoming impaired; it can cause children permanent damage physically and mentally, stunt and distort their development and destroy opportunities of fulfilment, including the roles they are expected to play successively as they get older in family, community and society (Gordon, Nandy, Pantazis, Pemberton & Townsend, 2003; Liliane Foundation, 2014). An estimation is that in Tanzania 8 to 10% of the population is living with an impairment (WHO, 2004). The WHO (as cited in Cameron et al., 2005) reported that infectious disease, like malaria or polio, is the main cause of impairments in Africa. Other major causes are: war, trauma, accidents, congenital and non-infectious diseases, malnutrition and poor quality of perinatal care.

People who live with an impairment face various challenges and barriers, preventing them from participating equally in society. In low income countries, these challenges are even bigger: the literature shows that impairments are often not managed in a satisfactory manner (Lehtomäki, Tuomi & Matonya, 2014; Njelesani, Couto & Cameron, 2011; WHO, 2011). When it comes to educational attainment and labour market outcomes, people with impairments in developing countries face a disadvantage compared to their healthy fellow citizens (WHO, 2011). Njelesani et al. (2011) report in their study that it is estimated that less than 40% of children with an impairment are enrolled in primary education, and less than 2% are included in special education programmes. Furthermore, accessibility of a safe physical environment is evaluated as poor (Lehtomäki et al., 2014; Njelesani et al., 2011). Moreover, physically impaired children experience even more participation restrictions than children without a physical impairment (Piškur et al., 2012).

However, some families seem to do well despite the extra challenges an impairment brings. Social support and strong family cohesion, amongst other things, might influence the outcome (Cohen & Hoberman, 1983; Saloviita, Italinna & Leinonen, 2003; Taanila, Jarvelin & Kokkonen, 1999).

Parental support

Support can be described as an interactive process in which particular actions or behaviors can have a positive effect on an individual's social, psychological, or physical well-being (O'Reilly, 1988). Social support might help people to cope with stressful situations by assisting them to change the situation, to change the meaning of the situation, to change the emotional reaction to the situation, or to change all three. Social support is proven to be a positive influence to someone's health (Cohen & Hoberman, 1983; Thoits, as cited in Moritsugu, 2014). Social support can be subdivided into different types of support. The most common subdivision is to explain support as a combination of informational,

instrumental and emotional support. Informational support occurs when one individual helps another to understand a stressful event better and to ascertain what resources and coping strategies may be needed to deal with it. Instrumental support involves the provision of tangible assistance such as services, financial assistance, and other specific aid or goods. Emotional support involves providing warmth and nurturance to another individual and reassuring the person that he or she is a valuable person who is cared about (Taylor et al., 2004). Research shows that social support within the family can act as a mediator against the negative effects on well-being, associated with an impairment (Migerode, Maes, Buysse & Brondeel, 2012; McConnell, Savage & Breitreuz, 2014; Schulz & Decker, 1985). However, Sipal et al. (2009) emphasize that the context of families influence the level of provided support. They report that financial, psychological and social resources may affect the extent to which parents are able to ensure optimal emotional and behavioral functioning of their child.

CURRENT STUDY

In order to examine the level of provided parental support for children and adolescents with a physical impairment in northern Tanzania, and to investigate the influence of their social environment, the following two research questions were formulated:

- In what ways do parents in northern Tanzania support their physically impaired children?
- What factors in parents' social environment determine the level of provided support?

The literature mentioned above will be used to structure the interviews and the outcomes of this study. In composing the topic lists, the Network of Relationship Inventory (NRI; Furman & Buhrmester, 1985) will be consulted. Questions will be selected and formulated based on their intercultural value. The types of support that will be imposed are instrumental and emotional support. Instrumental support will be subdivided into informational, material and practical support; and emotional support will be subdivided into companionship, sharing, comfort and conflict. As Taylor et al. (2004) explained, instrumental support involves the provision of tangible assistance such as services, financial assistance, and other specific aid or goods. Therefore, in this study, informational support is seen as an aspect of instrumental support.

METHOD

The support provided by parents and the influence of their social environment were measured through semi-structured interviews and open observations. First, 36 face-to-face interviews were conducted with children and adolescents with a physical impairment and their parents. Second, twelve interviews were conducted with professionals who work closely with these children and parents, five of them being mediators of the local Partner Organizations of the Liliane Foundation. All interviews were

conducted by using interview topic lists. Furthermore, open observations and informal talks were included for processing and interpreting the results.

Participants

Data was collected in March and April 2015 in three districts in northern Tanzania: Moshi, Sengerema and Musoma. The districts and organizations were selected by the contact person of Team English Africa from the Liliane Foundation in the Netherlands. In each district, a mediator working at the organization was selected to translate during the interviews. The translators were selected based on their knowledge of the English language and the extent of engagement with the children and their parents. The mediators were also the ones to select the children and parents to be interviewed.

Parents and children from three different regions in northern Tanzania were asked to cooperate in the data collection. The aim was to interview both biological parents of the selected children, but due to the passing of a parent, parents' divorce, or other reasons of absence, for some only one biological parent was interviewed (Table 1). Participants were contacted by the mediators. All of the approached participants responded positively and were happy to cooperate. However, it was sometimes hard to get in contact with the parents. Due to poverty, some of them were not in possession of any communication tools, which made making an appointment with them a challenge. Meetings for the interviews were then scheduled via community members.

Table 1. *Participants per region*

Region	PO	Number of children	Number of mothers	Number of fathers	Number of professionals
Kilimanjaro	Salve Regina Disabled Youth Fund	6	5	4	4
Mwanza	Disabled People's Organizations	5	5	3	4
Mara	Lake Victoria Disability Center	4	3	1	4
Total		15	13	8	12

Note. PO = Partner Organization

Interviews: procedure and topics

Semi-structured interviews were conducted to find out what kind of support parents provide for their children and what factors influence these different kinds of support. Interviews were conducted at the organizations or at family homes and took about 30-60 minutes each. All interviews were recorded using a voice recording device. The interviews started with an introduction of the people present and an

explanation of the subjects for discussion. The participants were asked to sign a consent form and had the opportunity to ask questions. The consent form stated in Swahili as well as in English what the provided information and voice recordings would be used for. The consent forms are included in appendices 1 and 2.

Interviews were held individually, in the presence of two interviewers and one translator. Most children and parents spoke their official language, Swahili, which was subsequently translated into English by the translator. In order to enhance the instrumental validity of the examples, precautions were made: first, the topic lists were introduced to local staff of the organizations in order to increase the cross-cultural validity; second, the interviews have been piloted several times in order to ensure that participants understood the examples correctly. Furthermore, in order to clarify the questions about practical support, images were used when interviewing parents and children. For each question, participants were asked to point out which of the two images applied to them. An example of the interview tool is shown in Figure 2, whereas all other images that were used are included in appendix 3.



Figure 2. Example of interview tool.

Topics

Topic lists were composed using the Network of Relationship Inventory (NRI; Furman & Buhrmester, 1985). Topics for discussion were more or less the same for parents, children and professionals. The only difference was that the topic lists for professionals consisted of questions which concerned parents of children with impairments in general, whereas the questions for the parents and children were about their specific situation. The topic lists are included in appendices 4, 5 and 6.

First, some general questions were asked to gather background information on the participants. Second, interviews consisted of questions on different types of support: instrumental support, subdivided into informational, material and practical support; and emotional support, subdivided into companionship, sharing, comfort and conflict. In conclusion, questions were asked about participants' past and future. Most questions that were asked using the topic lists lead to answers about the provided support only. In order to gather information on the influence of social environment, supplementary questions were asked.

Reliability and validity

In this study, various barriers compromised the reliability and validity. First, due to the language barrier all interviews were conducted with the help of a translator. It is possible that during translation information has been changed or lost. Furthermore, the presence of translators may have affected the interviews since translators were local staff members. Knowing that they were the ones providing them with social and financial support, socially desirable answers may have been given by the participants. However, translators' presence was also very much appreciated; they made participants feel comfortable enough to share personal information.

Another reliability issue regarding language was that even though staff members spoke English very well compared to the participants, their language skills were not adequate. During the interviews a lot of questions needed further explanation and examples. As a result, some questions may not have turned out to be as open as intended. Furthermore, because not all parents were able to come to the organization, some interviews were conducted at family homes (see Image 1). A disadvantage of this way of interviewing is that family or community members were present during some of the interviews (see Image 2). This may have influenced the answers given by participants. Another difficulty in collecting reliable answers were the cultural differences. Especially the questions regarding the different roles of fathers and mothers in supporting their children sometimes lead to giggle and confusion. Even the translators needed to be persuaded from time to time to literally translate the question.



Images 1 and 2. Interviewing participants at home.

In order to minimize social desirability, triangulation was used, which means that different views were taken into account. First, face to face interviews with the children were conducted. Second, parents were interviewed separately. Third, local staff members were interviewed to provide information on how parents support their impaired children in general. Overall, information provided by children corresponded to information provided by their parents. Furthermore, in order to maximize the reliability of translations, interview questions were discussed with translators in advance of the interviews to make sure they understood the aim of the study. These discussions were also used to emphasize that even though some answers may have seemed rather obvious or self-evident to the participants and to translators themselves, questions needed to be answered and recorded in order for the information to be

included in the research. Moreover, when answers were insufficient, supplementary questions were asked concerning examples or specific situations. Finally, in addition to the interviews open observations and informal talks were included for processing and interpreting the results.

Data processing

Even though supplementary questions provided more information on the influence of social environment, data analysis revealed that information provided by children on this topic was insufficient. Therefore, in answering the first research question, all interviews will be taken into account, whereas only the interviews with parents and staff members will be used to answer the second research question. Furthermore, data analysis showed that it is impossible to describe the results based on the subdivision that is used for emotional support. The distinction between different types of emotional support is not clear in the given answers. Therefore, only the subdivisions informational, material, practical and emotional support will be represented.

RESULTS

The aim of the current research was to find out what kind of support parents in northern Tanzania provide for their physically impaired children, and in what ways their social environment influences the provision of support. The topic lists were drawn up by using different types of support. The results of the data collection will be represented according to these types of support in four sections. Within each section the different thoughts of participants will be presented. First, to give an idea of the living conditions of the participants, background information about their environment will be given.

Living conditions

Most of the interviews were conducted at organizations' head offices. Due to a number of reasons, not all parents and children were able to come to the office, so they were visited at their family homes. It was very informative to have a glance at their personal life, to see how they live and to get a better understanding of their everyday struggles. The families that were visited live in poor circumstances. They live in small houses, with many family members (see Images 3 and 4).



Images 3 and 4. Houses of participants.

Most houses are built with sundried or baked bricks, but 23.5% of households in Tanzania Mainland use poles and mud for the construction of walls (NBS, 2015). The poor economic circumstances in Tanzania constitute a serious danger to people's health. The NBS report (2015) shows that a large percentage of people use pit latrines as toilets, drink water from unprotected sources, use kerosene as the main source for energy of lighting and firewood for cooking. This was also the case for the families that were visited for the interviews.

In Tanzania, farming is an important source of income. With few exceptions, all parents that were interviewed are farmers. They own a piece of land where they grow vegetables and fruits, either to sell on the market or for domestic use. With so many people being farmers, competition is high and income is low. Moreover, climatic fluctuations have a great impact on the production of food. Tanzanian citizens face serious problems of either flooding or lack of rain. One mother reported that she wanted to grow and sell bananas in order to be able to buy things for her daughter. However, because of a shortage of water she has not been able to keep a garden up to now. The climatic situation influences more than just the production of food. Many people in Tanzania live far away from important government buildings like schools and hospitals. Their houses are situated far from main roads and are only accessible via long, often narrow, sandy roads (see Image 5). They travel long distances for work, spending a lot of time away from their families. During rainy season, many roads become impassable, making it a challenge for people to get to work or to school. As one mother in Moshi stated: *“During sunrise, I escort her to school, but if it's raining she doesn't go to school”*.



Image 5. The road to a family's isolated house.

PROVIDED SUPPORT

Overall, the interviews showed that all types of support were provided to a certain degree by parents. The types of support that were mentioned most frequently by participants were material and emotional support. Practical support was also mentioned several times, but informational support did not seem to be provided that often. Results will be discussed per type of support. In addition, quotes from participants are literally cited in order to clarify the results.

Instrumental support

Informational support

Informational support is not very often provided for children. Children reported that they do ask their parents –most of the time their mothers- about their impairment, but the only answer they receive is that they were born with it. Parents don't actually provide their children with information, instead they just try to make them feel comfortable with themselves and their physical impairments. This corresponds to what parents stated in their interviews. As one father in Sengerema answered, when he was asked about talking to his child about his impairment: *“I always encourage him to feel well as other children because he is not different from other children”*.

Professionals reported the same about informational support: in general, parents do not talk to their children about the impairments enough. They try to encourage them and to make them feel happy, but information provision should be better.

Practical support

Overall, children reported that they don't receive a lot of practical support from their parents. Most of them stated that they bathe themselves, dress and go to school by themselves. However, there are a few exceptions. Children with missing, paralyzed, or extremely malformed limbs, indicated that their parents help them with several activities like bathing or getting dressed. Preparing food is the only thing that none of the children can do. Mothers are the ones cooking meals in most families, with few exceptions of children learning how to cook porridge or tea themselves. Furthermore, children reported that they need help with homework sometimes. They try to do it themselves at first, but if they have questions they ask their parents.

Interviews with parents showed that children indeed manage to do a lot of practical things by themselves. However, in contrast to what children reported, a lot of parents explained how they help their children when they don't succeed themselves in the first place. This applies especially to bathing and getting dressed. One mother in Moshi said: *“It took some time but even after he was not clean. So I just tell him that I need the container to do something else so I tell him I will help him in order to be done earlier”*. Other parents stated that they help their children by getting water and soap for washing, or by laying out their clothes for them. This is also what staff members reported about practical support.

Material support

Material support is one of the two types of support that is mentioned most by children. It is striking that a lot of these children are sponsored by the Lilliane Foundation to get an education and everything that is needed for school. Yet, most children mentioned their parents to be the ones buying them school uniforms and paying for their school fees. Parents on the other hand, reported that the school fees are indeed paid for by the Lilliane Foundation while the parents are responsible for most other school supplies and basic needs. This corresponds to what staff members stated in their interviews. They

reported that most parents don't pay for school fees themselves, but they do ask parents for some sort of contribution, like firewood or maize.

When it comes to food and clothes, all participants reported that parents are the ones providing their children with basic needs, where possible. However, there appears to be a difference in material support provided by fathers and by mothers. Whereas in two-headed households it is often the father who is responsible for the financial support, in single parent households mothers have a hard time supporting their children materially. Even more than parents who live together, single mothers rely upon financial support from the Liliane Foundation or other donors.

Emotional support

As mentioned earlier, most parents put a lot of effort in trying to make their children happy. According to the interviewed children, parents talk to them about their lives and their future, they encourage them to do well in school and to make the best of the situation as it is. Again, mothers were mentioned more often in providing their children with emotional support than fathers. A boy in Musoma said, when he was asked about spending time with his father: *"I always tell my father that he should turn on the video for me. I want to play with my father but he says I should play alone"*. However, there are also children that reported playing sports or board games with their fathers while mothers are busy with domestic activities.

Parents mentioned doing domestic activities together. They also talk to their children about life, school and religious matters. In general, parents also know what makes their children happy or sad. Parents reported to comfort their children when they are sad and they try to look for ways to make them feel happy again. They do this by buying them new things or by letting them go to school and to church. Furthermore, all parents expressed a lot of worries about their children's future. They know that one day they will pass away and they have big concerns about what will happen to their child after they have passed away. Overall, parents reported that children do share their happiness and concerns with them. As one mother in Sengerema said: *"When he has got a problem he talks to me. When he needs something he tells me. So I know that our relationship is good"*.

Interviews with local staff members showed that most children with physical impairments spend their time with their mothers. They assist their mothers by doing domestic activities, they talk together and mothers try to encourage their children in various ways. Information on the issue of sharing feelings with parents varied among staff members. Some stated that children talk about their feelings with parents, whereas others said that they do not talk about this at home.

DETERMINANTS OF PROVIDED SUPPORT

Data analysis revealed different factors from the social environment that determine the level of support that parents provide for their physically impaired children. The most frequently mentioned

determinants were: information provision, poverty, lack of time, beliefs and culture, of which beliefs can be subdivided into: religious beliefs and superstition. Table 2 carefully summarizes the level of influence that these factors have on the provision of support. The factors that were reported most, and thus have a great influence on the level of provided support, will be discussed per type of support. However, since culture is of such great influence on all different types of support, this factor will be discussed in a separate paragraph.

Table 2. *Mentioned level of influence on type of support*

Type of support		Participants	Information provision	Poverty	Lack of time	Beliefs	Culture
Instrumental	Informational	Parents					
		Professionals					
	Practical	Parents					
		Professionals					
	Material	Parents					
		Professionals					
Emotional		Parents					
		Professionals					

Note. = great influence = moderate influence = little or no influence.

Instrumental support

Informational support

One of the most frequently mentioned factors that determines whether parents do or do not support their children with physical impairments, is the provision of information. Lack of information has a great influence on the level of informational support given by parents. All professionals and most of the parents that were interviewed, reported that they do not have enough information about the impairments of their children. Due to budget limitations of the organizations, the seminars, workshops and trainings that are organized are usually small and not accessible to all parents. Furthermore, parents repeatedly stated that they have nowhere to go if they have questions. Others said that they do have a place to go, but they feel that their concerns are not adequately addressed. Besides the ability to ask questions, they would like to be trained on how to live with an impaired child. The few parents who did attend a seminar or training of some sort, indeed emphasized the importance of information provided by hospitals, organizations and governments. One mother reported that she received the correct information about the impairment of her child directly at birth, which made it possible for her to pass the information on to the child and to discuss the consequences together, as soon as the child started to ask questions about her impairment.

Professionals, just like parents, pointed out the importance of information provision. One staff member in Moshi reported that there is a church that teaches parents how to take care of their impaired

children. She stated that parents who did not attend this training, often do not even know what kind of impairment their child has. Other staff members also emphasized that a lot of parents do not talk to their children about the impairment, because they simply do not have the right information to share with them. One of the staff members in Moshi talked about the positive effects of the seminars that they organize. She said: *“They [the parents] said that after the seminar, when coming, they started to teach them [the children] to go everywhere, even those who have wheelchairs were brought near to do this, do this. And now they are appreciated and integrated in activities in the home place”*. Ensuring that the available information reaches the parents, is one of the challenges pointed out by a staff member in Musoma. As he said: *“It’s not like in developed countries; not everyone has a television, radio, newspapers. If people cannot access these things you don’t expect them to be well informed”*.

In addition to lack of information, interviews with parents revealed another factor as a determinant of provided informational support: religious beliefs. Religion plays a large role in the lives of people in Africa. Whether things are good or bad, they are what they are because God wanted them to be that way. This way of thinking also applies to having a child with a physical impairment. This can be seen as a positive way of thinking and dealing with difficult situations. However, interviews with parents showed that religious belief can be a limiting factor when it comes to supporting their impaired children. Whereas on the one hand, religion gives parents hope and security in times of uncertainty, it also keeps them ignorant to some extent. A lot of parents stated in their interviews that there is nothing they can do to change the situation, because it simply is as God wants it to be. This keeps them from obtaining information and informing their children.

Practical support

“Mother would go out to find something to eat and would sometimes come home late and found Erick already peed on himself because there was no one to help him”. This is what a divorced father in Moshi reported in the interview about the time his son was still living with his mother. It is one of many profound statements that parents, as well as some staff members, have given. Due to poverty, a lot of parents spend their days far from home looking for ways to provide their families with basic needs. For the parents who are raising their children together, there usually is some sort of division of tasks. But for single parent households, there is often no time left to spend with the children. Without the help of family members or people from the community, there is no alternative but to leave the child at home while looking for a way to make money.

However, as many staff members pointed out, it is not just a lack of time that determines the level of provided practical support. A lot of parents deliberately choose not to spend time with their impaired children. Although some professionals that were interviewed spoke of both parents, many reported fathers to be the ones leaving the house for other activities, while mothers stay at home. As one local staff member in Moshi reported: *“Mothers can take care of their children, but fathers see it as wasting their time. They see it as a person who cannot do anything”*.

Furthermore, staff members mentioned superstition to be of great influence to the level of provided practical support. Superstition works in various ways: in a positive way when parents think something bad will happen to them if they don't care for their children. As one local staff member in Moshi said: *"You know, as African, if you are not taking care they know you will get something very bad. Because they believe that when you are not taking care of the disabled, God will give you something bad"*. In a negative way, when parents refrain from the care of their children because they believe they are bewitched. A staff member in Musoma said about superstition: *"There are people who believe if they have a child with a disability, some parents would say maybe this is witchcraft. So there is no point in taking the child to the medical hospital for examination, but go to a witchdoctor who would also give very unique quality of medical attention, which will not work, instead it might make things worse"*.

Material support

Both professionals and parents, mentioned poor economic circumstances as one of the biggest challenges for parents of impaired children. One father in Moshi talked about the inability to pay for his daughter's school fees, he said: *"But because the rain season had come we sent her to the boarding school. I could not pay for these school fees because boarding school is more expensive than the other school"*. So, without the help of the Liliane Foundation he would not have been able to send his daughter to boarding school. Some parents even reported that they sometimes have to tell their children that they will not be able to eat that day.

Staff members reported that parents often do not have the necessary money or transport to take their children to the hospital or to provide them with good education. One of the local staff members in Moshi stated: *"The parents I know are just farmers, they have nothing to pay, they don't have enough food. So the poverty makes people, especially the disabled, to suffer a lot"*. Nevertheless, interviews with professionals also revealed another side to this situation: many parents deliberately choose not to spend money on their impaired children. This has to do with multiple factors. First, according to local staff members, parents feel as if providing their impaired children with material support is a waste of their resources. They think there is no point in paying for school fees or other supplies, since the children are not able to do anything for them in return as they grow older. One of the local staff members in Musoma stated about material support: *"Some have money, but don't see a child with a disability as being able to contribute. They do pay the school fees for the other children, but not for the one with disabilities"*. Second, parents are aware of the fact that their impaired children are being sponsored by either the Liliane Foundation or another organization. This is why they decide to spend the money that they have on their children without impairments, since they are not being sponsored.

Emotional support

Parents as well as staff members stated that the main reason for parents not to spend time with their physically impaired children, is because they do not have that time. As mentioned earlier, parents

often spend a lot of their time away from home to generate income. Interviews showed that in general, mothers spend more time at home than fathers do. However, even mothers do not have a lot of time for supporting their children emotionally due to domestic activities and other everyday tasks, like farming. In addition to a lack of time, again, some parents deliberately choose not to spend time on their physically impaired children. As a local staff member in Moshi stated: *“Those with disabilities are very much disliked. The parents think they are wasting their time and resources caring for a child with a disability”*.

Another important determinant of the provision of emotional support is belief. Religious beliefs as well as superstition have great impact on the level and type of emotional support that is provided for physically impaired children. Interviews showed that there are positive as well as negative influences of religion. Information provided by participants showed that often when a child is sad, instead of comforting the child themselves, parents tell him or her to pray to God in order to feel happy again. However, the role of religion can also be complementary in comforting children. As a father in Sengerema said to his son when he was sad because of his impairment: *“We tell him that he is loved by God. Due to his situation God still loves him”*. This made the boy feel better.

As with religion, superstition is a determinant of emotional support which can be of both negative and positive influence. Some parents believe that having a physically impaired child brings good luck into their lives. As a mother in Moshi reported about her daughter: *“Since she was born, I have had a lot of fortunes and people are supporting me. She is a blessing, not a curse as people would think”*. On the other hand, when parents see their impaired child as a curse, it keeps them from taking care of him or her emotionally. A staff member in Sengerema said about this: *“They don’t accept the disability, because they think they might be witched. So they lock them inside the house. Others tie them up with ropes, or use chains so they can’t move. They don’t want to expose their children”*.

Culture

The African culture has its own common values and traditions. For example: women are supposed to raise children, whereas men are responsible for finding a job and generate income. All participants mentioned that fathers do not spend much time with their children, because they are away from home most of the day. For single parent households, where it is just the mother taking care of the children, this is an even bigger challenge. As one local staff member in Sengerema stated very clearly: *“Mothers don’t hold the cash, the man does. Mothers don’t have that power, that is culture. When the father is not there, the mother is often lost”*. Absence of fathers in families with impaired children was given a lot of attention in interviews with professionals. Local staff members repeated several times how in most families, the father runs away as soon as he finds out that he has a child with an impairment. Comments on this subject varied considerably. Whereas some staff members stated that this is due to a lack of knowledge on how to take care of an impaired child, others said that fathers simply do not want to waste time or resources on an impaired child. Superstition was also mentioned often as a reason for

fathers to leave the family. A local staff member in Sengerema said: *“They say the woman has done evil things. I don’t know why it is aimed at women, it has always been that way. Every traditional myth is about women”*. This explains why fathers run away, leaving the care of the children to the mother.

Besides the difference between fathers and mothers, a difference was also found in the provision of support for boys and girls. Local staff members pointed out in their interviews, that in some communities, physically impaired boys receive more support than physically impaired girls. The reason for this difference is that in the African culture, boys are the ones to come back home as they become adults, to support the family, whereas girls leave the family to get married.

Furthermore, culture determines the way in which children are supported emotionally. In the Western world, it is a common thing to discuss any imaginable subject at home. However, interviews showed that in Tanzanian families not everything is up for discussion. A staff member in Musoma stated: *“The issue of feelings is not well understood in Africa. It’s not anything that is given much attention that parents want to understand the inner feelings of a child and that it’s normal when they’re sad”*.

When a child is sad, parents often try to make him or her feel better by buying them something like food, or by telling them to pray to God.

CONCLUSION AND DISCUSSION

The current study examines how parents in northern Tanzania support their physically impaired children and what factors in their social environment influence the provided support. Data was collected in three different regions in northern Tanzania. Information was collected through 36 semi-structured face-to-face interviews with children and adolescents with a physical impairment and their parents, twelve interviews with professionals who work closely with these children and their parents, open observations and informal talks.

It can be concluded that all types of support are provided to some extent by parents. However, the level of provided support varies. Informational support is not very often provided for children. Children do ask questions about their impairments, but they rarely get any answers. With respect to practical support, some children who face the inability of doing practical things themselves due to extreme physical impairments such as missing, paralyzed or malformed limbs, rely upon help from their parents for bathing and getting dressed. However, most children are able to do everything themselves. Finally, material and emotional support are provided most often by parents, although the level of provided material support is very dependent on the economic circumstances.

The social environment of parents has a strong impact on the level of provided support. Factors that were mentioned most frequently are: information provision, poverty, lack of time, beliefs and culture, of which beliefs can be subdivided into: religious beliefs and superstition. Culture appeared to be the biggest determinant for all four types of support. The following cultural aspects were given a lot of attention by participants: division of labor between men and women, challenges for single parent

households due to the leaving of fathers, differences in provided support to boys and girls and the way in which thoughts and feelings are shared, and dealt with, within the household.

The reliability of results may have been affected due to the use of translators. Furthermore, limitations inherent to cross-cultural bias could not be completely avoided and could have affected the interpretation of the answers of participants. Social desirability could have influenced the answers of participants since translators were mediators from the Liliane Foundation, working closely with the children and their parents. In order to maximize the reliability of translations, interview questions were discussed with translators in advance of the interviews. In addition, social desirability has been minimized by using triangulation. Information was provided by three different sources, making it possible to cross-reference their responses. Whereas the types of support that are provided for physically impaired children may not apply to other African countries, the factors from social environment that influence the level of provided support are very likely to be the same. To ensure improvements in this area, some recommendations are discussed.

The results of this study strengthen previous findings. Several studies have mentioned lack of information provision, poverty, beliefs and culture as limiting factors in the support that impaired children receive (Cameron et al., 2005; Lehtomäki et al., 2014; Njelesani et al., 2011; Piškur et al., 2012). In non-Western, developing countries, children often have more economic value to their parents than in Western societies (Eldering, 2006). Parents invest in their children in order to profit from them as they grow older and are no longer able to generate income themselves. This explains why some parents refuse to spend money or time on their impaired children. In order to reduce the negative effects of limited financial, psychological and social resources, education may need improvement.

Parallel study

In addition to this study, Den Uijl (2015, in preparation)¹ carried out a parallel study to investigate parental support for intellectually impaired children. Local staff members were interviewed about children with intellectual as well as physical impairments. Overall, interviews show that parents provide less informational and emotional support to intellectually impaired children than to physically impaired children. This is due to the fact that intellectually impaired children experience difficulties in expressing themselves, making it hard for them to communicate with their parents and vice versa. However, because of their mental restrictions, they receive more practical support than physically impaired children. Finally, interviews show that intellectually impaired children and adolescents have to deal with even more discrimination due to superstition than children with a physical impairment.

¹Den Uijl, M. (2015). Parental support towards children and youngsters with an intellectual disability in northern Tanzania (Master thesis in preparation). Education, socialization and youth policy, Faculty of Social Sciences, University of Utrecht, Utrecht.

Recommendations

Due to lack of time and other restrictions regarding this Master thesis, not all aspects have been given the attention they should have. Parental support, especially facilitators and barriers in the African context, need further investigation. Although staff members emphasize that the provision of information to children has improved over the past few years, this study shows that education is insufficient. Seminars and training for parents as well as entire communities, could increase knowledge on causes and consequences of impairments, and thereby decrease the influence of religious beliefs and superstition. Provision of information may even affect the attitudes of fathers, preventing them from leaving their families due to a lack of awareness.

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Appendix 1. Consent form child

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

Appendix 2. Consent form adult

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...:

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

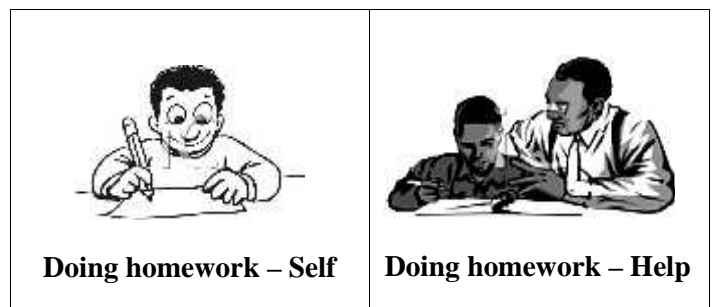
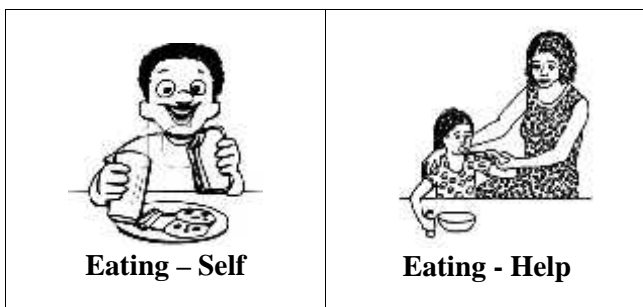
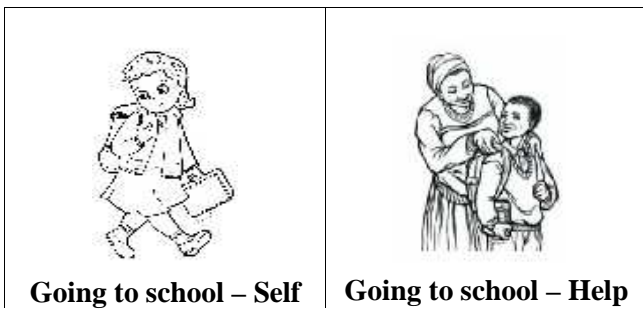
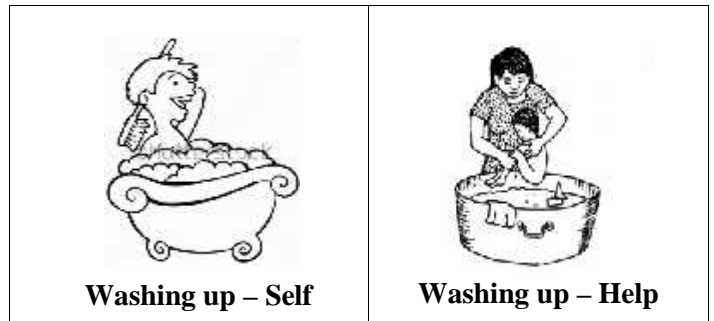
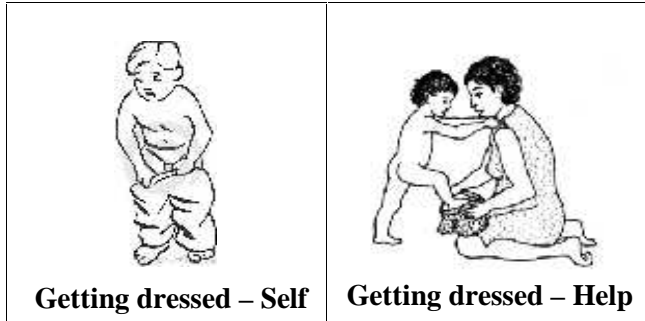
* **Taarifa hii haitatangazwa kwa watu / This information will be published**

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:

Appendix 3. Images used during interviews with children and parents



Appendix 4. Topic list child

CHILD	
GENERAL QUESTIONS	
G1 <i>Name</i>	-
G2 <i>Gender</i>	-
G3 <i>Age</i>	How old are you?
G4 <i>Education</i>	Do you go to school? Which school? What grade?
G5 <i>Number of siblings</i>	How many brothers and sisters do you have?
G6 <i>Living situation</i>	With who do you live at home?
INSTRUMENTAL SUPPORT	
I1 <i>Informational</i>	Who do you talk to about your disability? - If caregiver, how does he/she react? - If someone else, why not caregiver?
I2 <i>Practical</i>	Here are some pictures of daily things. Can you point out what things you can do yourself and what you need help with?
I3 <i>Practical</i>	You say you cannot do this by yourself. Who helps you with it? a) If caregiver: How does he/she help you? b) If someone else: Why not your caregiver?
I4 <i>Material</i>	Who provides you with schoolbooks and school fees? b) If someone else: Why don't you help?
I5 <i>Material</i>	Who provides you with food? b) If someone else: Why don't you help?
I6 <i>Material</i>	Who provides you with clothes? b) If someone else: Why don't you help?
EMOTIONAL SUPPORT	
E1 <i>Companionship</i>	How much time do you spend with your caregiver?
E2	What do you do together? b) Do you talk together? - If yes, what about? Can you give an example? - If no, why not? c) Do you play/laugh/joke together? - If yes, can you give an example? - If no, why not?
E4 <i>Comforting</i>	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?
E5 <i>Sharing</i>	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?
E6 <i>Conflict</i>	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 you caregiver(s)? - Is there anything you would like to change about the relationship?	
OPTIONAL	

USE
PICTURES

O1	<i>Past</i>	What was the situation like when your father/mother/parents were still alive/around?
O2	<i>Future</i>	How do you see your future? What do you want to be when you grow up?

Appendix 5. Topic list adult

CAREGIVER	
GENERAL QUESTIONS	
G1	<i>Name</i> -
G2	<i>Gender</i> -
G3	<i>Age</i> How old are you?
G4	<i>Education</i> What education did you receive?
G5	<i>Occupation</i> What do you do for a living?
G6	<i>Religion</i> What religion are you?
G7	<i>Number of children</i> How many children do you have? How old are the youngest and the oldest?
G8	<i>Marital status</i> Are you married? [What happened to the husband/wife?]
G9	<i>School child</i> Does your child go to school? Which school?
QUESTIONS ABOUT DISABILITY	
D1	Can you describe your child's disability to us?
D2	What do you think caused the disability?
D4	When and how did you find that your child was different than other children? What did you do?
D5	How does the community respond to the disability? Do you feel like that affects your relationship/daily life?
INSTRUMENTAL SUPPORT	
I1	<i>Informational</i> Do you feel like you have enough information about how to handle/live with the disability?
I2	<i>Informational</i> If you have questions about the disability, what do you do? [Who do you go to?] b) Do you talk to your child about the disability?
I3	<i>Informational</i> In what ways do you help your child to cope with his/her disability?
I4	<i>Practical</i> 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?
I5	<i>Practical</i> You say he/she cannot do this by him/herself. Who helps him/her? b) If someone else: Why don't you help? c) If caregiver: How do you help him/her?
I6	<i>Material</i> Who provides the child with schoolbooks and school fees? b) If someone else: Why don't you help?
I7	<i>Material</i> Who provides the child with food? b) If someone else: Why don't you help?
I8	<i>Material</i> Who provides the child with clothes? b) If someone else: Why don't you help?
EMOTIONAL SUPPORT	
E1	<i>Companionship</i> How much time do you spend with your child?
E2	What do you do together? b) Do you talk together? - If yes, what about? Can you give an example? - If no, why not? c) Do you play/laugh/joke together? - If yes, can you give an example? - If no, why not?
E3	Can you describe your child's character?
E4	<i>Comforting</i> 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	<i>Conflict</i> Are you ever mad or upset at him/her? Can you give an example? When that happened, what did you do?

USE
PICTURES

E6	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?
OPTIONAL	
O1 <i>Past</i>	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 <i>Future</i>	How do you see the future of your child?

Appendix 6. Topic list professional

PROFESSIONALS	
GENERAL	
G1 <i>Job</i>	What is your job?
G2 <i>Organization</i>	For what organization?
G3 <i>Employment</i>	How long have you been working here?
G4 <i>First contact</i>	- How do you get in contact with the children the first time? Do you find them, or do they find you?
G5 <i>Contact</i>	- How much contact do you have with children with disabilities? - How much contact do you have with the parents/guardians?
G6 <i>Caregiver</i>	- In general, who are the main caregivers of children (at home)?
G7 <i>General support</i>	- In what ways do parents support their children with disabilities?
INFORMATIONAL	
I1 <i>What's going on</i>	- Do you feel like parents have enough knowledge about the child's disability? - Do parents have a place/people to go to when they have questions about the disability? - Do they talk about it with their children? - Who else provides the child with information about their disability? - 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?
I4 <i>Mental vs. phys.</i>	- Is there a difference in the information provision from parent to child with mental or physical disabilities?
PRACTICAL	
P1 <i>What's going on</i>	- In what ways do parents support their children practically? - How? Example? - In general, who helps the child most with practical things, like getting dressed, eating, moving around etc.?
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?
P4 <i>Mental vs. phys.</i>	- Is there a difference in the practical support provision from parent to child with mental or physical disabilities?
MATERIAL	
M1 <i>What's going on</i>	- In general, who provides the child with schoolbooks and school fees? - In general, who provides the child with 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?
M4 <i>Mental vs. phys.</i>	- Is there a difference in the material support provision from parent to child with mental or physical disabilities?