# Outcomes of a Rehabilitation Program for Adolescents with a Physical- or Hearing Impairment in the Central Region and Volta Region in Ghana

# Outcomes of a Rehabilitation Program for Adolescents with a Physical- or Hearing Impairment in the Central Region and Volta Region in Ghana

A qualitative study of the changes in daily life activities, communicative activities and social participation after the intervention sponsored by the Liliane Foundation



#### Master thesis

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We wish you a pleasant reading, Karin Rozendal and Karin van Trijp

#### **Abstract**

**Background:** The Liliane Foundation supports organizations that provide interventions for children and adolescents with an impairment in Ghana. The outcomes of this aid are not fully known. **Purpose:** This study aims to describe to which extent adolescents from 15 to 25 years old with a physical- or hearing impairment have experienced changes in their daily life activities, communicative activities and social participation since the intervention sponsored by the Liliane Foundation and how they perceive those changes. Additionally, the barriers that the adolescents are still facing after the intervention are investigated. Method: A qualitative approach is used. In total we conducted 37 semi-structured face to face interviews with the adolescents and some parents, 4 interviews with staff members and 7 focus groups. For additional information document analysis and open observation were done. The discussed topics were based on the domains of the International Classification of Functioning, Disability and Health. Results: The adolescents could move around or communicate more easily, had more friends, were learning something or had found work. These changes were caused by surgery, the use of aid devices, attending school or a training, learning sign language and a change in mind set. Several barriers towards full participation were still present, such as stigma's about impairments, a bad infrastructure and parents that did not understand how to deal with the impairment of their child. Conclusion: All participants have experienced changes in their daily life activities, communicative activities and social participation after the intervention. However, the adolescents were still experiencing infrastructural, attitudinal and educational barriers and therefore could not always participate in their family and community. Keywords: outcomes, adolescents, physical impairment, hearing impairment, Ghana

#### Introduction

Worldwide there are millions of children and adolescents with an impairment. The United Nations Children's Fund (UNICEF, 2005) estimates the worldwide prevalence to be 150 million children under 18 years old, while the World Health Organization (WHO, 2011) estimates that there are 93 million children with an impairment aged 14 years or younger. According to UNICEF (2005) 80 to 85% of children with an impairment live in developing countries. The WHO (2011) states that, particularly in these countries, having an impairment hinders the access to education, health care and special care.

According to article 23 of the Convention of the Rights of the Child, a child with an impairment should enjoy a full and decent life with dignity, self-reliance and participation in the community (United Nations [UN], 1990). The Convention on the Rights of Persons with Disabilities (UN, 2008) states the need to promote and protect the human rights of all persons with an impairment, including those who require more intensive support.

The Liliane Foundation is a Dutch non-governmental organisation that strives to empower children and adolescents up to 25 years old with an impairment in Africa, Asia and Latin America. The foundation collaborates with local organizations to improve the functioning of children and adolescents with an impairment, eliminate barriers to participation and empower the children and adolescents to become agents of change in the society. Generally, these organizations offer interventions that are adapted to the individual medical-and social needs of children and adolescents (Liliane Foundation, 2013).

Currently, the Liliane Foundation is searching for a tool to measure the outcomes of interventions for the involved adolescents. According to the Organisation for Economic Cooperation and Development (2010), outcomes are the likely or achieved changes of an intervention's output. These outcomes can be expected or unexpected and positive or negative.

The main partner organization of the Liliane Foundation in Ghana, Samuel Wellington Botwey Foundation (SWEB), is aiming to measure the outcomes for their local interventions. The Liliane Foundation as well as SWEB have indicated that they would like to have more information about what changes have occurred regarding the activities and participation of the adolescents after they received the intervention. Therefore, the purpose of this study is to gain knowledge about which changes have occurred in the activities and participation of adolescents with an impairment in Ghana since the intervention and how they perceive those

changes. Due to limitations and a lack of time to include all types of impairments, this study focuses on adolescents with a physical- or hearing impairment. By choosing these target groups this study includes an observable and an unobservable impairment. The researched domains are therefore limited to daily life activities, communicative activities and social participation.

We will not be able to define the outcomes as causal effects of the intervention, because of a lack of time and available pre-tests. Moreover, it would not be ethical to include a control group. For these reasons, we will define the outcomes as changes perceived by the target group, which does not imply that the changes are resulting from the intervention. In this view, the outcomes can provide information about which factors can create change in the activities and participation of an adolescent with an impairment. The results can directly indicate what kind of adaptations may improve the intervention.

The following research questions will be answered:

- To which extent have adolescents from 15 to 25 years old with a physical impairment in the Central- and Volta region in Ghana experienced changes in their daily life activities and social participation, since the intervention sponsored by the Liliane Foundation?
- To which extent have adolescents from 15 to 25 years old with a hearing impairment in the Central- and Volta region in Ghana experienced changes in their communicative activities and social participation, since the intervention sponsored by the Liliane Foundation?
- Which barriers are the adolescents currently facing?
- Which change is considered to be the most significant by the adolescents themselves?

### **Impairment and Disability**

The terms 'impairment' and 'disability' are often used interchangeably. However, according to several studies (Barnes, 1991, as cited in Bickenbach, Chatterji, Badley, & Üstün, 1999; Hughes & Paterson, 1997; Oliver, 1996) these terms have another meaning. Hughes and Paterson (1997) state that impairment refers to the biological dysfunction, while disability refers to processes of social exclusion. Oliver (1996) outlines that impairment refers to the physical body, whereas disability refers to the society. Barnes (1991, as cited in Bickenbach et al., 1999) uses disability when referring to social restriction as a result of an impairment.

As a result of much criticism by scientists about not having a clear and accepted definition for each of these concepts, the WHO (2001) has developed the International Classification of Functioning, Disability and Health (ICF; Stucki, Cieza, & Melvin, 2007). This framework defines impairment as abnormalities of body functions or structures. Disability encompasses limitations in activities and restrictions in participation as a result of the impairment. According to Stucki (2005) this framework is likely to gain global acceptance in medicine and rehabilitation science, especially since it has worldwide cultural applicability and addresses many of the criticisms of previous conceptual frameworks. For this reason, this study will use the definitions of impairment and disability as defined in the ICF.

# Having an Impairment in Ghana

It is estimated that 3% of the total population in Ghana has an impairment (Ghana statistical service, 2012). According to the Samuel Wellington Botwey Foundation (SWEB, 2013) these statistics probably underestimate the true numbers, because of cultural barriers. For example, people with an impairment can be kept hidden, which implies that they are not included in those percentages. The most common types of impairment in the country are visual impairments, followed by physical impairments, emotional and behavioral disorders, intellectual impairments and hearing- and speech impairments (Ghana statistical service, 2012; SWEB, 2013). These proportions also count for children and adolescents (Ghana statistical service, 2013).

Physical impairment is a term that can be used for a wide range of impairments. This study focuses on physical impairments that can influence mobility, such as impairments of legs and arms. Having a physical impairment may have consequences for an adolescent in

daily life tasks. Roberts and Lawton (2001) conclude that most children and adolescents with a physical impairment need assistance with washing, dressing and eating. Additionally, people with a physical impairment in Ghana can experience difficulties in their mobility. This is explained by Reynolds (2010) who states that the streets of Ghana are not very accessible by lacking ramps and sidewalks for people with a physical impairment.

The social consequences of having a physical impairment vary per child. The study of Stevens and colleagues (1996) show that adolescents with a physical impairment do have as many friends as adolescents without a physical impairment. However for people with a physical impairment the friends are mostly limited to the ones in school. Several studies (Anaby et al., 2013; Law, Petrenchik, King, & Hurley, 2007; Shikako-Thomas, Majnemer, Law, & Lach, 2008) conclude that children and adolescents with a physical impairment may experience environmental barriers to participation, especially for after school activities. These barriers are found in buildings, transport and the natural environment. Children and adolescents with a physical impairment can also experience attitudinal barriers from the family and community (Law et al., 1999). For example, children and adolescents with a physical impairment are frequently overprotected by their parents, which can limit their independence (Heah, Case, McGuire, & Law, 2007).

A hearing impairment is defined by the grade of hearing loss. This study will focus on adolescents with a profound impairment, including deafness. They have an audiometric value of 81 decibel or greater and are unable to hear and understand a shouted voice (WHO, 2014). According to the WHO (2006) about two third of people with a hearing impairment live in developing countries. Olusanya, Ruben and Parving (2006) show that annually 2 to 4 babies per 1000 are born with a hearing impairment in developing countries. This may extend to six per 1000 in the neonatal period.

Ramkalawan and Davis (1992) and Robinshaw (1996) show that a moderate bilateral hearing impairment of more than 40 decibel can hinder language, speech and cognitive development when the impairment has its onset in early childhood. The acquisition of literacy skills, speech and language development are founded by an adequate auditory stimulation (Fisch, 1983), because the 'critical phase' from birth to 5 years old is important for the acquisition of language (Carney & Moeller, 1998). Irreversible deficits in any of these developments are associated with failure in detecting and effectively managing a hearing impairment (Kennedy et al., 2006; Moeller, 2000; Olusanya, Luxon, & Wirz, 2004).

According to Carney and Moeller (1998), infants that are identified with a hearing impairment

after 6 months of age have worse language outcomes than infants that are identified before 6 months of age and are supported appropriately. Moreover, because of the hearing impairment, academic, social and emotional development may be adversely affected (Culbertson & Gilbert, 1986; Mohr et al., 2000). According to Moeller (2007), an individual's perceived quality of life and interpersonal relationship may be affected by the negative influences of a hearing impairment. For example, Culbertson and Gilbert (1986) show that children with a hearing impairment have less peer relations and social confidence. As Davis, Elfenbein, Schum and Bentler (1986) state, children with a hearing impairment express concerns about being accepted socially and making friends. According to Culbertson and Gilbert (1986) these children are often rated as not initiating interaction with peers and they are more frequently distracted in the classroom.

One of the consequences of an having an impairment in Ghana can be increased poverty. According to The World Bank, in 2006 about 28.5% of the inhabitants of Ghana lived below the national poverty line (1.25 dollar per day). The poverty in the rural areas is the highest with 39.2% of the inhabitants who live below the national poverty line against 10.8% in the urban areas (The World Bank, 2013). People with an impairment are more likely to be poor when compared to people without an impairment. Palmer (2011) states that by needing assistive devices, personal care and more healthcare than an average person, people with an impairment have higher daily costs than people without an impairment. Moreover, Ghai (2001) and Palmer (2011) argue that later in life, children with an impairment will most likely experience a low level of education, will be unemployed or working hard for low payments. According to Palmer (2011), this can be the direct result of the impairment, but can also be caused by discrimination from and barriers in the society. Not only people with an impairment, but also their family can be discriminated. For example, in Ghana, an individual's identity and behavior is linked to the identity of the family (Anthony, 2011), which therefore affects the family having a child with an impairment in their productivity and is a social mark of infamy and shame (Reynolds, 2010).

#### **Causes of Impairments in Developing Countries**

People living in poverty are more likely to get an impairment because of several reasons.

According to a literature review of Elwan (1999), poor nutrition, limited access to healthcare and low living and working conditions are factors that contribute to the development of

impairments among poor people. In general, the amount of people with an impairment seems to be higher in rural areas than in urban areas. This can be explained by a longer distance to healthcare facilities and higher poverty rates in rural areas (Harris-White & Subramanian, 1999). Conflicts and accidents are also a big cause of impairments for poor people, because people with an impairment more often practice a dangerous job and live relatively often in an area with a high probability of being a victim of crime (Groce et al., 2011; Harris-White & Subramanian, 1999). Additionally, when these people get injured, it is less likely that they are able to pay for the medical care that is needed to treat the injury in order to prevent an impairment (Groce et al., 2011).

According to the study of Reynolds (2010) the beliefs about the causes of impairment differ among the Ghanaians. Some of the Ghanaians know that impairments are caused by medical or environmental factors like birth, sickness or an accident, but there are also people in Ghana who believe that an impairment is for example a curse on the family caused by an ancestor that did something wrong. Spiritualism and taboos are prevalent in a lot of communities in Ghana, even in the more educated and developed regions (Reynolds, 2010). Ghanaians use spiritualism as the medium to make sense of and understand their daily experiences, values, social identity and destiny (Dei 2004; Kuada & Chachah, 1999; Salm & Falola, 2002; Utley, 2009).

Physical impairments can be caused by infections and diseases, like meningitis, polio, HIV, malaria and leprosy (Durkin, 2002; Parnes et al., 2009). Trauma from land mines and hazards and involvement in road accidents can cause physical disabilities as well. Moreover, according to Durkin (2002), a lack of micronutrients such as folate, ionine and vitamine A can cause physical impairments. Several authors (Durkin, 2002; Parnes et al., 2009; Tamrat, Kebede, Alemu, & Moore, 2001) state that many physical impairment can be prevented through vaccinations and immediate medical care, maternal awareness, healthy nutrition and safer traffic. However, because of the poor conditions in developing countries, these preventive methods are limited. Therefore, physical impairments are more common in developing countries when compared to developed countries (Durkin, 2002; Parnes et al., 2009).

Permanent hearing impairments are attributable to genetic and environmental causes. The WHO (2006) states that 50% of the diagnosed hearing impairments are probably preventable. However, Schroeder and colleagues (2006) state that prevention services such as maternal and child health services, immunization and health education have limited

effectiveness in preventing neonatal hearing impairment caused by genetic factors. Other causes of hearing impairment may be in-utero infections such as herpes, rubella, cranio-facial anomalies, toxoplasmosis and syphilis (American Academy of Pediatrics, 1999). According to the United States Joint Committee on Infant Hearing (American Academy of Pediatrics, 1999) other risk factors are bacterial meningitis, ototoxic medications, stigmata, birth weight less than 1500 gram and mechanical ventilation lasting five days or more. Moreover, a chronic discharging ear is a familiar illness during childhood, which may also cause a hearing impairment (Okafor, 1984).

### Aid to People with an Impairment

# Medical Model versus Social Model

Aid to people with an impairment can be seen from a medical and a social perspective. The medical model has been the dominant model for many years. According to Alur (2001) this model sees disability as a problem of the individual and assumes that the child requires medical treatment and rehabilitation to be able to participate in the community. Llewellyn and Hogan (2000) state that this model derives from the disease model that is used in medicine, which says that a disease needs appropriate treatment. It relies on the idea that a human being is flexible, while the society is not. According to Llewellyn and Hogan (2000), the individual should adapt to its environment. Hutchison (1995) criticizes the medical model because it assumes that children with an impairment are automatically disabling their family. For example, Hutchison (1995) observed that families with a child with an impairment can fully accept and love their child.

With the view of Hutchison in mind, disability cannot be understood without the social context (Marks, 1997). The social model, therefore, states that disability is socially constructed, which means that the society disables people with an impairment by discrimination and fails to adjust the society to the impairment (Gatrell, 2002; Hutchison, 1995). This model indicates that people with a physical impairment for example, are put more at a disadvantage by the attitudes of the society than by their loss of function (Hutchison, 1995). That is why an intervention based on the social model of disability focuses mainly on making the society and/or community more inclusive for people with an impairment. This can be reached through attitudinal and physical (ramps, elevators et cetera) change of the society.

### Inclusion of People with an Impairment in Ghana

According to Reynolds (2010), in Ghana there is disagreement about the responsibility of helping people with an impairment, since other problems of the country have to be taken into account. Additionally, there is no consensus about what the basic rights entail and who has the responsibility to apply and plan new policies (Reynolds, 2010). International movements are accountable for the pressure and competing priorities in Ghana (Anthony, 2011). The government of Ghana has ratified the 'Rights of Persons with Disabilities' and 'Education for All' and provides inclusive education for marginalized students (Ghana Education Service 2005). To fulfill the goals of 'Education for All' there was a rapid expansion of enrollment in basic education (Avoke, 2001), which caused overcrowded classrooms and a shortage of qualified teachers (Akyeampong, 2008). According to Anthony (2011) this will have a negative impact on proper inclusive education for children and adolescents with an impairment. She concludes that international declarations should not only be adopted, but also adapted and implemented in a way that is consistent with the local conceptualizations of impairments.

In May 2012 there were 7006 children with an impairment in special schools and 21,000 in integrated schools. However, education is still inaccessible to many children and adolescents with an impairment in Ghana. This can be assigned to a lack of appropriate facilities, inaccessible environment for wheelchairs, teachers untrained in special needs in regular schools and unavailable learning materials for children and adolescents with special needs (SWEB, 2013).

Reynolds (2010) notes that attempts to include people with an impairment are opposed by spiritual beliefs. Even when Ghanaians are open to the idea of including people with an impairment at school or work, they are skeptical about their abilities to fulfill the work at the same level as a non-impaired person. People with an impairment are discriminated by employers (Reynolds, 2010), whereby the situation of women with an impairment is even worse, because of their impairment and gender (Naami, Hayashi, & Liese, 2012).

#### Community-Based Rehabilitation

Aside from promoting special- and integrated schools, a way to provide aid to people with an impairment in developing countries is through Community-Based Rehabilitation (CBR). This form of rehabilitation addresses both the medical and social needs of persons with an impairment (Lightfoot, 2004). Therefore, not only the rehabilitation specialist or trainer is

concerned with the rehabilitation, but also the community in which the person with an impairment lives (Mitchell, 1999). The study of Lagerkvist (1992) concludes that effective CBR has at least a system for community involvement and cooperates with disability organizations.

The aim of CBR is to empower people with an impairment to live as independently as possible and to be full and equal members of the community (Finkenflugel, 2006; Pollard & Sakellariou, 2008). The WHO (2004) distinguishes two major objectives of CBR. First, the aim is to ensure that people with an impairment are able to optimize their mental and physical abilities, so that they can access regular services and opportunities and can become active contributors to the community and the whole society. Second, the aim is to stimulate communities to promote and protect human rights of people with an impairment by removing barriers for participating in the community.

Lightfoot (2004) states that CBR is considered to be a sustainable and affordable form of rehabilitation, since it uses local community members to run the program. However, the study of Pollard and Sakellariou (2008) has found that the involvement of community members is often limited. Velema, Ebenso and Fuzikawa (2008) conclude that CBR is most beneficial to people with mild physical impairments, who can communicate verbally.

#### **Evaluating a Rehabilitation Program for Adolescents with an Impairment**

#### Bronfenbrenner

According to Bronfenbrenner (1977), a person's development is determined by the entire ecological system in which it lives. Therefore, Bronfenbrenner (1994) states that when the development of a person is studied, all the layers of this system should be addressed. These four layers include the micro-, meso-, exo-, and macrosystem. The microsystem contains the personal characteristics, roles and the immediate surroundings of the child. The sex, age, health and physical environment of the child are examples of this microsystem. The mesosystem is explained to be the interaction between multiple microsystems and includes the linkages and processes taking place between for example the school, family, peers and health services.

According to Bronfenbrenner (1977), activities of a person are part of the microsystem. Participation covers the mesosystem of the adolescent. Since this study focuses on changes in activities and participation of the adolescents, the data collection is focused on

these two systems. The exosystem and macrosystem of the adolescent are less targeted in this study, because in these systems the adolescent is not an active actor. However, these systems can influence the adolescent, so observations, theoretical background and focus groups could give information about the reasons why an adolescent can or cannot do certain activities or to which extent he or she is participating.

#### ICF-framework

Several studies (Jelsma, 2009; McConachie, Colver, Forsyth, Jarvis and Parkinson, 2006) conclude that the ICF is a good framework for determining the functioning of children and adolescents with an impairment. The WHO (2002) developed the ICF-framework for describing and organizing information on functioning of persons with an impairment. The domains of the ICF are based on functioning and contextual factors. This study focuses on two domains of functioning: activities and participation.

The ICF published a list of topics that should be investigated to determine the activities and participation of a person with an impairment. For this study we used the topics of this list that cover the domains daily life activities, communicative activities and social participation. This implies that for adolescents with a physical impairment the following daily life activities will be included: mobility, self-care and domestic life. The topic 'methods of communication' will be used to investigate communicative activities for the adolescents with a hearing impairment. The topics related to social participation are: relationship with family, relationship with friends, school, work, leisure time, relationship with community and attending religious places.

#### Method

#### Design

The perceived changes of the adolescents were measured through semi-structured interviews, document analysis, open observation and focus groups. In total we conducted 37 face-to-face interviews with adolescents with a physical- or hearing impairment, and their parents when they were present, as well as four interviews with staff members of the organizations. Additionally, two focus groups were held with people without an impairment and five focus groups with people with an impairment.

### Selection of Organizations and Participants

To get in contact with the participants, three organizations were visited. All were chosen by the main partner organization of the Liliane Foundation. The first organization was situated in the Central Region. This organization worked according to the CBR principle, so it offered aid to the adolescents in their community, but also had an office where the clients pass by for regular checks and repairs of the aid devices. The contact person pointed out some adolescents to visit, but the researchers have also selected some adolescents randomly. The same contact person was also interviewed for additional information about the organization and the method of working. The interviews were held at the adolescents' home, school or at the organization. It was possible to ask questions to eight parents. Additionally, one focus group was held with adolescents without an impairment and three focus groups with people with an impairment.

The two other organizations were situated in the Volta Region. Both were institution based organizations. One was focused on inclusive education for adolescents with a physical impairment and adolescents without an impairment. The adolescents were randomly selected for the interviews through a list of names. The focus group with adolescents with a physical impairment was also selected through a list of names, while the participants of the focus group with adolescents without an impairment were selected by one of the staff members. At this organization two staff members were interviewed. All interviews were held at the organization. At this organization, it was possible to interview one parent. The other organization was focused on children and adolescents with a hearing impairment. The adolescents were selected by a staff member for the face to face interviews and the focus group. The focus group existed of adolescents with a hearing impairment. Also one interview with a staff member was conducted.

By selecting the participants, it was taken into account that the variables age and sex of the participants were equally distributed. More specific information about the participants can be found in appendix A. Overall, it was not difficult to find participants for the interviews. However, sometimes the interviews were canceled, because the adolescents were not at home. One interview could not be used in the analysis, because the adolescent did not seem to be motivated to give proper answers and the researchers had the impression that the translation was not well done.

#### Procedure

The topics that were addressed during the interviews with the adolescents were based on the topics of the domains 'activities' and 'participation' of the ICF. The topics for daily life activities consisted of mobility, self-care and domestic life. Communicative activities contained the topic: methods of communication. The topics for social participation comprised relationship with family, relationship with friends, school, work, leisure time, relationship with community and attending religious places. For each topic the current situation and the situation before the intervention was asked and in case of change the cause of the change was investigated. Afterwards, each participant pointed out which change was the most important for him or her. The detailed topic list can be found in appendix B. To visualize the topics and to guide the adolescent through the interview, images were used for each topic. An example is shown in figure 2, all the other images can be found in appendix C. Smileys were only used as supportive material when a participant had difficulties to answer a question or to get more indepth information about a topic.

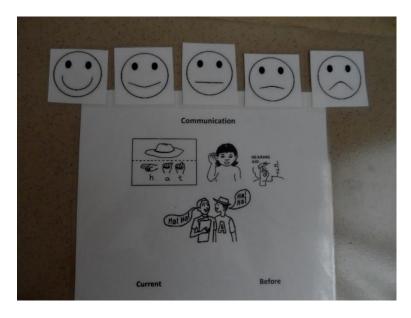


Figure 2. Example of interview tool.

All interviews were conducted between February and April 2014. The interviews took 15-30 minutes each and were held by both researchers. Before, during and after the interviews, open observation was used to indicate how the participant was functioning socially and physically. Additionally, it was observed whether the physical environment was accessible for the participants.

To get more understanding about social participation and discrimination of people with an impairment in Ghana, focus groups have been conducted. The discussed topics during these group interviews were: knowledge about the causes of impairments, experiences with discrimination, acceptance and inclusion of people with an impairment. The complete topic

list can be found in appendix D. Also, for each organization at least one staff member was interviewed to gain additional information about the organization and their working methods. The general questions are shown in appendix E, but were adapted for each interview.

Aside from the interviews and focus groups, for each adolescent that was interviewed his or her personal rehabilitation file was analyzed. In these files information about the current situation and the situation at the beginning of the intervention could be found. These documents were written by the staff members. The files also contained information about which support the adolescent received and when he or she received it.

To guarantee the anonymity of the participants, all interviews and the document analysis were made anonymous. Before each interview, the participants were told about our research and had the possibility to ask questions. The parents or supervisors of the participants under the age of 18 were asked to grant permission before the interview was held. Also, most interviews were conducted after school hours to avoid disturbing the adolescents during their classes.

#### Reliability and Validity

Due to cultural differences and considering that most participants were not used to see white people, one local staff member was always attending the interview. This person knew the participant well enough to have the trust of the participant and was able to explain the questions to the participants if they were not understood because of different cultural backgrounds. In most cases this person also did the translation from English to local language or sign language. However, the presence of this local staff member could also have caused socially desirable answers since most adolescents knew that the staff member was providing the social and financial support. Moreover, since all but six interviews were translated from local language or sign language to English, information might have been lost or changed during translation.

In some places in Ghana, impairment is a taboo subject. This could have led to incomplete or socially desirable answers. Additionally, when parents or community members were present during the interview the chances for socially desirable answers were increased.

To reduce the possible negative influences on the reliability, this study used triangulation. This means that several sources of information were collected about the same topic. First, face to face interviews with the adolescents were held. Second, in case the parents were present during the interviews, they were asked to give additional information on the

adolescent's situation. Third, open observation before, during and after the interviews was used to try to indicate socially desirable answers and the adolescent's capabilities and behavior. Fourth, focus groups were held to get more understanding about participation and discrimination of people with an impairment in Ghana. Fifth, the staff member was asked about the adolescents and additional information about the intervention. Last of all, we conducted an analysis of the personal rehabilitation files of the interviewed adolescents. Table 1 shows which methods were used to gather information for each topic. When conflicting data were found, the data were only used when the majority of the sources were representing similar information. For example, one interview has not been included in the results because we doubted the quality of the translation and the motivation of the participant.

TABLE 1.
Triangulation for each topic.

	Face to face	Parent	Open observation	Focus Group	Staff member	Document Analysis
D 11 116 41 141	interview					
Daily life activities						
Mobility	X	X	X		X	X
Self-Care	X					X
Domestic life	X	X				X
Communicative activities						
Methods of communication	X	X	X		X	X
Social participation						
Relationship with family	X	X	X	X	X	X
Relationship with friends	X			X	X	X
School	X	X	X	X	X	X
Work	X	X	X	X	X	X
Leisure time	X			X	X	
Relationship with community	X	X	X	X	X	X
Attending religious places	X				X	
<b>Most Significant Change</b>	X	X			X	

#### **Results**

# Adolescents with a Physical Impairment

# Changes in Daily Life Activities

All adolescents have experienced positive changes in their activities. For the adolescents that experienced a change in mobility, this meant that they were able to move around more easily than before the intervention. The causes that were indicated were physiotherapy, surgery and the use of aid devices. All adolescents that experienced changes in self-care were able to take care of their personal hygiene with less help or completely independently after the intervention. The causes of the changes differed from a more positive mindset, to less overprotection by the parents and increased mobility. The causes for the changes in domestic life were mostly physiotherapy, so being able to move around, and less overprotection by parents. The latter reason is explained in the following quote:

I was physically able to do most of the household chores by myself, but before the intervention my parents were not allowing me to do them ~ P1

#### Changes in Social Participation

Changes in participation were appearing the most for school. The positively experienced changes were caused by attending school, which the adolescents did not before the intervention. Some others were already attending school before the intervention, but were at the moment of interviewing attending a higher level of education. The negatively experienced changes were related to quitting school for various reasons, such as not performing well, while another adolescent had to quit school because the mother decided it and the last one stopped because of problems relating to the impairment. One participant was attending a vocational school because of his disability, while he would have been able to attend a senior high school according to his capabilities. However, his parents did not want to support him because of his impairment. One adolescent who was attending school was not happy at school because she got teased by her classmates and teachers.

Participation in the family was not a topic of change for most adolescents, because they indicated that the relationship with their family was good and used to be good. Only one participant noted that he experienced a positive change. Because of being able to walk, the family admired this development and was accepting the adolescent more.

The changes in participation with friends occurred because of being able to walk,

which meant that the adolescents were able to go out of the house and make friends at school or in the community. Most changes in work appeared because the adolescents could stop working and attend school instead. Additionally, some adolescents indicated they could work since they received a training, for example working as a seamstress after following a sewing training.

The adolescents who experienced changes in their participation in the community explained that since they could walk they could participate more easily. Some indicated that changes had occurred because they were less shy and were taking more initiative since the intervention. One adolescent indicated that participation in the community was more difficult because of increasing financial problems of the family. The adolescents that were attending church more often than before the intervention, said it was because it was easier to reach the church. This was because of using another device, improved physical ability or because of improved infrastructure.

#### **Barriers**

During and after the interviews the participants had indicated several barriers that they were still facing. The most frequently mentioned barrier was the traditional beliefs about people with a physical impairment. Many people believed that they were witches or were having an impairment because of a curse. This was preventing the adolescents from participating in their families and communities. The focus groups showed the presence of traditional beliefs as well. An example is an adolescent without an impairment who said:

Before I was afraid of disabled people, because I thought that if I would do bad to them, I would become like them. When I met a disabled person for the first time at this school, I was afraid. Now I'm not afraid anymore, because now I know that they are all humans.

Another barrier was living in a remote area. From these areas there were rarely cars going to the larger towns, so people had to walk to get out of their community. For people with a physical impairment this was very difficult or even impossible, especially during the rainy season, when the roads were muddy. For example, one participant had broken devices, but was not able to go to a place to let them be repaired.

A third barrier that was mentioned was that children and adolescents with a physical impairment were less likely to attend basic education. About half of the participants had not followed or finished their basic education, because of their impairment in combination with poverty or discrimination.

Fourth, some participants indicated that they were still experiencing pain. For example, one adolescent had problems with one leg and one hand. While the problems with the leg were treated, nothing was done for the hand.

#### Most Significant Change

The change that was experienced as the most important by the adolescents differed widely from person to person. The most named changes were: being able to walk and go around, being accepted and having friends, going to school and learn something, more interaction and less discrimination in the community.

# Adolescents with a Hearing Impairment

#### Changes in Communicative Activities

All adolescents with a hearing impairment have experienced positive changes in their communicative activities. These changes were related to attending the school for the deaf, because the adolescents learned sign language. The adolescents stated that they liked communicating with others and were able to give their own opinion now.

# Changes in Social Participation

Some adolescents indicated that their relationship with their parents had improved and that they did not experience discrimination within their families anymore since the intervention. Knowing sign language was the most common cause of the positive changes in interpersonal interactions and relationships with family. One adolescent experienced a negative change, because she had a baby and a financial strain in the family. She experienced more discrimination by her family.

The reasons for the positive changes in interactions and relationships with friends were attending the school for the deaf and learning sign language. The adolescents felt more accepted and had more friends after the intervention. Some explained that they had friends with and without an hearing impairment, but most adolescents had only friends with a hearing impairment.

The positive changes for school were because the adolescents had acquired sign language and had the opportunity to learn something. One adolescent experienced a negative change, because he had to stop school as a result of a lack of money.

Some adolescents had experienced a positive change for work, because of attending the school for the deaf and receiving work training. Since attending the school for the deaf, the adolescents did not have to work for their parents anymore. One adolescent had to stop school as a result of a lack of money for the transport to school. At the moment of interviewing, he worked as a shoemaker.

Some adolescents explained that at school there was time to do sports or other activities in leisure time. One participant explained:

Before I was doing the household chores, because my mother was always pregnant. I have 10 siblings, so I had no time to play and to do sports. But now in school I have time to play with others and to do sports ~ H18

The positive changes for the community, social and civic life, were due to knowing sign language and having more confidence to go outside their homes and participate in daily life activities. Some stated that they were not discriminated anymore and felt accepted.

The causes for the reported positive changes for attending religious places were different. One reason was that there was an interpreter during the mass so they were able to follow the mass. Another reason was that someone could go out of the house since the intervention and was therefore able to attend church.

#### **Barriers**

Some adolescents reported that they experienced barriers for having a good relationship with the family. One adolescent reported that his parents did not like him and was beaten, because his parents were frustrated about his impairment. Additionally, it appeared that most parents of the adolescents with a hearing impairment did not know how to use sign language. Therefore, communication between the adolescents and their parents was absent or very difficult. Some adolescents also indicated that their parents did not understand how to deal with their impairment.

Barriers were also found for relationships with the community. One adolescent indicated that there was no interpreter, so she could not hear the announcements when for example a community cleaning day was organized. Therefore, she was not updated about the community activities and was not able to participate.

Another barrier was the quality of teaching in the school for the deaf. In school the adolescents were taught through sign language, but not all staff members in the school of the deaf seemed to be fluent in sign language. Sometimes they received help from the students for a correct instruction to the class in sign language.

Lastly, the government prevented people with a hearing impairment to drive a car in Ghana, since it was forbidden by law. This became clear during an individual interview in which the adolescent noted that he wanted to become a taxi driver.

#### Most Significant Change

The change that was experienced as the most important for the adolescents with a hearing impairment was going to school to learn something and be able to do sports activities after school. The second most important was being able to communicate through sign language and thereby to give their opinion.

#### **Conclusion**

The Liliane Foundation is supporting organizations that provide interventions for children and adolescents with an impairment in Ghana. This study examined the outcomes of the intervention in the Central- and Volta Region for adolescents from 15 to 25 years old with a physical- or hearing impairment. The changes in the daily life activities, communicative activities and social participation of the adolescents were investigated through 37 semi-structured interviews with the adolescents and some parents, four interviews with staff members, document analysis, open observations and seven focus groups.

It can be concluded that all participants had experienced changes in both activities and participation since the intervention. The adolescents with a physical impairment were able to move around more easily, could take care of themselves more independently and could do more household chores. These positive changes were caused by physiotherapy, surgery, the use of aid devices and less overprotection by parents. The positive changes in social participation were mostly caused by being able to walk and going outside, because most adolescents were not able to do so before the intervention. The change that was experienced as the most important by the adolescents with a physical impairment differed widely from person to person. The adolescents with a hearing impairment also experienced positive changes in both their communicative activities and social participation. Most of these changes could be attributed to attending the school for the deaf. At this school the adolescents learned sign language, made friends and had time to do sports. The most important changes for adolescents with a hearing impairment were learning sign language and attending school.

This study showed that there were less positive changes in participation than in activities and most current barriers were linked to social participation of the adolescents. One of the most frequently mentioned barriers for adolescents with a physical impairment was

being discriminated by the community- and/or family members. Another barrier was living in a remote area, where is no proper infrastructure, which implied that the adolescent could not get out of the community. Adolescents with a hearing impairment experienced most barriers in the relationship with their family.

Most interviews were translated from local language or sign language to English, which might have had an impact on the reliability of this study. Moreover, socially desirable answers might have affected the results of this study. To increase the reliability, this study used triangulation to retrieve additional information about the adolescents' situation aside from the interviews and to check whether the answers given during the interview corresponded to information from other sources. Additionally, information that was considered unreliable was left out of the results.

The results of this study resembled results of other studies about people with an impairment. One of the resemblances with several studies (Anaby et al., 2013; Law et al., 2007; Shikako-Thomas et al., 2008) was that adolescents with a physical impairment experienced environmental barriers to participation. These barriers were found in buildings, transport and the natural environment. Ghai (2001) argued that children with a physical impairment most likely experience a low level of education. This was also confirmed during the interviews. Another similarity of this study and other literature was that the academic, social and emotional development of adolescents with a hearing impairment were negatively affected (Culbertson & Gilbert, 1986; Mohr et al., 2000).

#### **Discussion**

The participants had experienced changes in both activities and participation. However, there were less positive changes in social participation than in daily life- or communicative activities and most current barriers were linked to social participation of the adolescents. The adolescents who did not feel accepted in their society stated that factors such as discrimination and bad infrastructure had not changed since the intervention. These results can be linked to the views on disability. The Liliane Foundation has been supporting organizations that implement interventions based on methods that represent the medical model, which according to Llewellyn and Hogan (2000) implies adapting the person to the environment. This can explain why the outcomes were mostly based on improvements of the individual person, while the social context had not changed much. It is recommended to try to

focus more on the social model of disability, so that barriers for inclusion in the community could be reduced.

Working according to the social model implies to focus more on making the communities and society more accessible towards people with an impairment. Since discrimination was one of the most frequently named barriers, it is advised to focus on eliminating stigmas about people with an impairment. An example could be to spread more information amongst people in the communities about the causes of impairments. Another example could be to promote inclusive education. During a focus group with adolescents without an impairment who were attending a school for inclusive education, the adolescents indicated that their perception of people with an impairment had changed a lot since they attended the school. They stated that they were scared of people with an impairment before they attended the school, but learned in school that people with an impairment are 'normal' people as well. This could indicate that stimulating more inclusive education might lead to a more accepting peer group for children and adolescents with an impairment. For future research it could be interesting to examine the effects of inclusive education on social participation of adolescents with an impairment.

Another way of taking the social context into consideration is by including parents or caretakers in the intervention. A lot of adolescents were indicating that their parents still did not know how to deal with their impairment. This was especially the case for most parents of adolescents with a hearing impairment. These parents could only do some gestures, but no sign language. A recommendation could be to include the parents more during the rehabilitation and to teach them how to deal with the impairment of their child.

Recommending to focus more on the social participation of adolescents with an impairment does not mean that the intervention should lose its focus on improving the individual aspects. The adolescents that were included in their community indicated that it was a consequence of the improvements in their physical abilities or communication. Therefore, it seemed that social participation can be reached after improvement of activities has been reached and the person can move around and communicate with others.

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# Appendix A. Basic information about the participants

TABLE 2. Participants of the first organization.

Participant				
number	Sex	Age	Who interviewed?	Where?
P1	F	17	Adolescent	School
P2	F	19	Adolescent	Home
P3	F	20	Adolescent and parent	Home
P4	F	23	Adolescent	Home
P5	F	23	Adolescent and parent	Home
P6	M	?	Adolescent	Organization
H1	F	21	Adolescent and parent	Home
H2	F	15	Adolescent and parent	Organization
Н3	F	21	Adolescent and parent	Organization
H4	M	20	Adolescent and parent	Organization
H5	F	15	Adolescent and parent	Organization
Н6	F	18	Adolescent and parent	Home
H7	M	23	Adolescent	Organization
Н8	M	17	Adolescent	School
H9	M	17	Adolescent	School
H10	F	20	Adolescent	School
H11	F	21	Adolescent	School

TABLE 3.

Participants of the second organization.

Participation		
number	Sex	Age
P7	M	22
P8	M	23
P9	M	22
P10	M	22
P11	M	24
P12	M	23
P13	M	23
P14	F	25
P15	F	18
P16	F	21
P17	F	24
P18	F	21

TABLE 4.

Participants of the third organization.

Participant number	Sex	Age
H12	M	18
H13	M	19
H14	M	?
H15	M	19
H16	M	22
H17	M	22
H18	F	16
H19	F	16

### Appendix B. Topic list individual interviews with adolescents

#### **Introduction to the interview**

Hello,

We are Karin Rozendal and Karin van Trijp and we are students from the Utrecht University in the Netherlands. For our master research we are interested in what has changed in your life, since you have received the treatment from \*organization\*.

The interview will take about 30 minutes. If you agree, we will record this interview on a voice-recorder. We will not use your name when transcribing and reporting the interview so we will guarantee your anonymity and only use your answers for our research and not for any other purposes. You can tell us anytime during the interview that we should not publish a name or situation you told us about. If there is any question you don't want to answer or if you want to stop the whole interview, please let us know and we will respect your request.

Do you still have questions for now?

#### Introducing questions – 5 minutes

- Could you tell something about yourself? (age, living area/situation, impairment)
- When did you get into contact with the organization? (use name of organization that the participant is in contact with)
- What did the organization do for you? Is the organization still helping you or has the aid been finished at the moment?

#### Questions about the child's current situation—25 minutes

*Introduction towards the participant:* we would like to talk with you about changes in your life since you got in contact with the organization. We have several topics that we would like to discuss with you and for each topic we will ask you about your current situation and about the situation before you received help from the organization.

- Can you tell us how you move around? / How you pick up things?
  - → how was that before the treatment? What is the cause of the change?
- How do you communicate?
  - → how was that before the treatment? What is the cause of the change?
- To which extent can you take care of your daily needs, like toileting, washing, eating?
  - → how was that before the treatment? What is the cause of the change?

- Which household chores are you doing? (preparing meals/laundry/cleaning/taking care of others)
  - → how was that before the treatment? What is the cause of the change?
- Can you describe your contact with friends and family? And with teachers or doctors? → how was that before the treatment? What is the cause of the change?
- Do you go to school or work? Can you tell us more about this? (How do you like it? Can you participate in the class?)
  - → how was that before the treatment? What is the cause of the change?
- What do you do outside of school/work? (Playing with friends?, Working at home?, Do you do any sports?, Do you have any contact with your neighbors or other people of your neighborhood? How do you like your community? Do you attend church?) → how was that before the treatment? What is the cause of the change?

# <u>Most significant change – 5 minutes</u>

- Looking at all these changes you have experienced, which one do you think is the most significant? / Which one is the most important to you?
- Can you explain why this change was so important to you?

# **Extra questions**

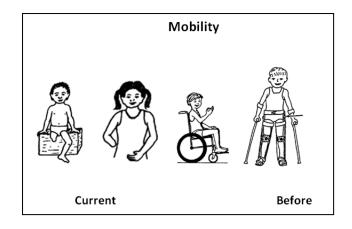
- Do you think that the answers you gave would also count for other children with an impairment in your neighbourhood?

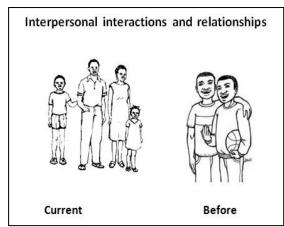
### **Closing**

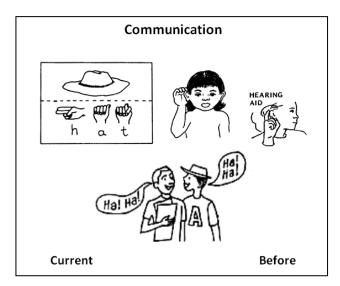
Do you still have any questions or do you still want to say something that we haven't talked about? Could we contact you another time if we still have questions from our side?

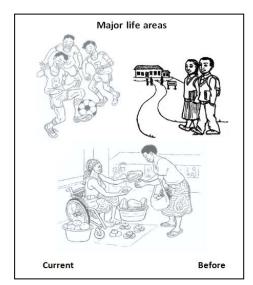
Thank you!

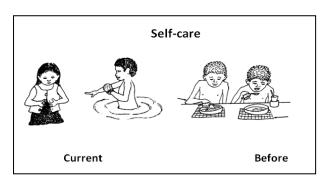
# Appendix C. Images used during individual interviews with adolescents

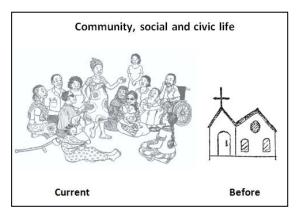


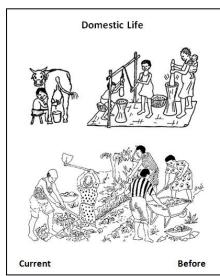












# Appendix D. Topic list focus groups

Participants: youngsters without an impairment

**Goal** = getting information about the view of people on persons with an impairment in their community

#### **Introducing questions** (individual)

- what is your name, age and occupation?
- do you know someone with an impairment?

# General questions (anyone can answer)

- What do you think that are the cause(s) of impairments? (in general)
- Do you have the impression that people with an impairment are treated different than people without an impairment? Can you give an example? / why yes or no?
- According to you, what is participation of people with an impairment in the community?
- How could people with an impairment be included in the community?
- What do you think you could do to include people with an impairment?

#### **Closing**

- do you have any questions or remarks?
- thank you for your time!

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# Participants: people with an impairment

**Goal** = getting information about the view of people on persons with an impairment in their community

#### **Introducing questions**

- what is your name, age and occupation?

#### **General questions**

- What do you think that are the cause(s) of impairments? (in general)
- Do you have the impression that people with an impairment are treated different than people without an impairment? Can you give an example? / why yes or no?
- According to you, what is participation of people with an impairment in the community?
- How could people with an impairment be included in the community?
- What do you think people without an impairment could do to include people with an impairment?
- What do you think you could do to include people with an impairment?
- Do you think your impairment will have an impact on your future? If yes, will that be positive or negative? (work, relationships, starting a family)

#### **Closing**

- do you have any questions or remarks?
- thank you for your time!

# Appendix E. Topic list interview with staff members

# **Personal questions**

- For how many years are you working for the organization? And for how many years in this position/function?
- What education did you follow to be able to practice this job?
- Are there any topics that you would like to learn more about?

# **Work related questions**

- How do you reach 'new' children with an impairment?
- How or by whom is assessed what kind of impairment a child has? For example, how do you determine if someone is deaf or hearing bad? Are you the only responsible or are there other people responsible for the assessment?
- To which extent do you involve the children in the needs assessments and IRPs?
- Once you have assessed new children, how often do you visit them?
- What does community awareness training consist of? (who is doing it, how long does it take, what do you discuss with people, how do you discuss it, when are you doing it, how do people respond to that? Can we maybe join once?)
- How do you decide whether a child needs continuous aid, or that you stop the aid?
- What kind of changes do you think are the most important for a person? (functionality / activities / participation) And why?
- After interviewing several children/youngsters we discovered that not everyone with the same intervention is experiencing the same changes / development. What do you think are the major factors for these differences?