Facilitators' Networks in Community Based Rehabilitation of Children with Physical Disabilities

An Exploration of the Availability and Non-usage of Needed Services

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MASTER YOUTH, EDUCATION AND SOCIETY

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Preface

Hereby I proudly present my thesis on the CBR facilitators' network in the Philippines. This thesis is the result of my master research for the track *International Pedagogical Issues,* which is part of the master *Youth, Education and Society* at the University of Utrecht. I experienced the collection of the data as pleasant and interesting, and enjoyed the analysis of the data and writing of this thesis. During data collection and writing this thesis, I improved my English writing skills, cultural sensitivity, and qualitative research and analysis skills.

Before proceeding to my thesis, I would like to thank the Liliane Foundation for offering me the chance to do my internship and research at their organization. I would especially like to thank my supervisors Anneke Hofs and Karin Rozendal for guiding me, advising me on my research methods, and providing me with insight in the CBR strategy. Furthermore, I would like to thank Willie Houben for arranging my visit to the Strategic Partner Organization in the Philippines.

My stay in the Philippines was very pleasant, and well arranged. This was made possible by the NORFIL Foundation, who arranged the visits to their Partner Organizations, and welcomed me when with open arms when arriving in the Philippines. I would especially like to thank Tes and Joan, for receiving me, guiding me the first days in Manila, and providing the Partner Organizations with information on my visit. Furthermore, I would like to thank the Partner Organizations for receiving us, for their hospitality, and for arranging the interviews with CBR facilitators and the children and their families. Of course I would also like to thank the facilitators that participated in the research, and the children and families who participated and welcomed me in their houses.

Last but not least I would like to thank two people who played an essential role in the establishment of this thesis. First, I would like to thank my supervisor dr. Dian de Vries for her advice, helpful feedback, and patience and supportive words when I was confused during the analysis of the data. Secondly, I would like to thank my fellow student, fellow researcher and friend Lynn van Duurling for visiting the Philippines and conducting the interviews together, the brainstorm moments, and last but not least, the pleasant and fun time we spent together.

Nijmegen, June 24, 2016

Samenvatting

Deze thesis richt zich op de behoeften van kinderen met een fysieke beperking en analyseert hoe het netwerk van CBR facilitators hierbij aansluit. Er wordt onderzocht welke verklaringen er zijn voor het ontbreken van faciliteiten in het netwerk van facilitators, en er is aandacht voor verklaringen van ouders en kinderen voor het niet bezoeken van beschikbare faciliteiten. Er hebben semigestructureerde interviews plaatsgevonden met 16 facilitators om hun netwerk in kaart te brengen en verklaringen voor het ontbreken van faciliteiten in hun netwerk te vinden. Ook zijn 30 kinderen en hun ouders geïnterviewd om hun behoeften vast te stellen. Er zijn verklaringen gevonden voor het ontbreken van faciliteiten in het netwerk, namelijk het gebrek aan kennis over beschikbare faciliteiten, een tekort aan therapeuten, een gebrek aan verantwoordelijkheid bij de lokale overheid, en een gebrek aan samenwerking tussen organisaties. Daarnaast zijn er verklaringen gevonden voor het niet bezoeken van faciliteiten door ouders en kinderen. Zij bezoeken faciliteiten niet omdat ze te ver weg zijn, te duur zijn, er geen tijd is om de faciliteiten te bezoeken, of de vervoerskosten te hoog zijn. Tot slot weten ouders soms niet van het bestaan van faciliteiten af. Al met al kan geconcludeerd worden dat het merendeel van de faciliteiten in de netwerken van de facilitators zit, maar dat er vooruitgang geboekt kan worden door rekening te houden met de geïdentificeerde factoren die een rol spelen, zoals de afstand tot faciliteiten, de samenwerking tussen organisaties, de kosten van faciliteiten en het vergroten van kennis over beschikbare faciliteiten.

Abstract

This thesis focuses on the needs of children with a physical disability, and analyses how the CBR facilitators' networks match these needs. Explanations for the unavailability of facilities in the facilitators' networks are identified. Furthermore, reasons of parents and children for the non-usage of available facilities are examined. To identify the CBR facilitators' networks and explanations for the unavailability of facilities, 16 semi-structured interviews were conducted with CBR facilitators, and 30 semi-structured interviews with children and their families. The results of the research indicate there are several explanations for the unavailability of facilities in the facilitators' networks, namely a lack of knowledge about available facilities, lack of responsibility of the local government to establish facilities, a lack of therapists and a lack of cooperation between organizations. Furthermore, children and their families do not visit facilities because they are located far away, the transportation costs are too expensive or the facilities themselves are too expensive. Lastly, parents are sometimes unaware of the existence of those facilities. In conclusion, most facilities are included in the facilitators' networks, but progression can be made if the identified factors are taken into account, for instance the geographical distance to facilities, the cooperation between organizations, the costs of facilities and the enhancement of knowledge on available facilities.

Keywords; Community Based Rehabilitation, CBR facilitators, network, physical disabilities.

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Facilitators' networks in Community Based Rehabilitation of Children with physical disabilities: An exploration of the availability and non-usage of needed facilities.

The World Bank estimates that about one billion people have got some form of disability (WHO & The World Bank, 2011). The majority of people with disabilities (PWDs) live in developing countries, under conditions of poverty (WHO, 2010a). There is a relationship between poverty and disabilities, as people who are disabled often experience more difficulty in finding work and often are excluded from activities in the community. Also, people living in poverty are at greater risk of getting a disability, since they do not have access to neither appropriate health care, nor nutrition. Moreover, PWDs do not have equal access to health care facilities, education or work as people without disabilities do (WHO, 2010a). As a result, it can be concluded that PWDs experience more difficulties than people without disabilities in providing in their own basic needs. They also may need more assistance or access to special facilities.

Especially children with disabilities (CWDs) need access to special facilities to help them function in society, such as assistance in access to health care facilities, social care or equal access to education (Abbott, Townsley, & Watson, 2005). Governmental units can provide these facilities, but in practice these facilities often are provided by non-governmental organizations, which work according to particular strategies. One of the strategies that strives for equality for PWDs, and tries to facilitate children with the help they need, is the Community Based Rehabilitation strategy (CBR strategy). This strategy focuses on the needs of people with disabilities and their families.

The CBR strategy is implemented by making use of CBR facilitators, who play an essential role in the referral of children to facilities they need. The referral of children to facilities they need, is an essential step in the rehabilitation process. In order to refer children to facilities, facilitators should know which facilities are available, and establish a network

with available facilities. Therefore, this thesis focuses on the network of the CBR facilitator and the usage of facilities by children.

The objectives of this thesis are to identify if the facilitators' networks are sufficient to provide the needs of children with physical disabilities, to find explanations for the unavailability of certain facilities, and to find explanations for the non-usage of needed facilities by children and their families. These objectives contribute to the improvement of the CBR strategy, by enhancing the insight in factors that play an essential role in the establishment of networks and enhancing the knowledge on factors that influence if families are visiting certain facilities. These insights can guide facilitators in improving their networks and enhancing the availability and usage of facilities, which are the practical implications of this thesis research.

Thus far, there is a limited understanding about which facilities should be included in the CBR facilitators' networks, in order to provide the needs of children with physical disabilities and their families. Further, there is little known about factors that influence the establishment of facilitators' networks. Available literature only provides insights in factors that influence the establishment of networks of health professionals, namely community characteristics and comprehensive knowledge on available health facilities. However, there is little to none literature which provides insight in factors that influence the CBR facilitators' networks and factors that influence children and their families for visiting available facilities. For this reason this thesis aspires to contribute to an insight in these factors, which makes it theoretically relevant, since the referral process is an important step in the rehabilitation process.

In order to provide insight in the facilitator's networks, and the factors that influence the facility usage, first the needs of the target group will be identified. Thereafter will be examined whether the facilitators' networks are sufficient in offering the needed facilities or

not. Furthermore, explanations for the unavailability of facilities, and the non-usage of facilities will be addressed. This all contributes to an answer on the main question of this thesis "*Which factors play a role in the availability and usage of facilities for children with physical disabilities and their families?*".

Community Based Rehabilitation Strategy

The CBR strategy was initiated in 1978 by the World Health Organization (WHO) in order to improve the access to rehabilitation facilities for PWDs in developing countries (WHO, 2010a). The strategy can be defined as "a strategy within general community development for rehabilitation, equalization of opportunities and social inclusion of all people with disabilities" (ILO, UN, & WHO, 2004). The strategy strives to offer PWDs access to these facilities by making use of local resources and to tackle the barriers within the community that exclude people with disabilities. The PWDs, as well as their families and communities, are involved in the CBR strategy (WHO, 2010a).

The CBR strategy strives to meet the basic needs of PWDs, to reduce poverty, and enhance their access to facilities on the five CBR domains. The five domains included in the CBR matrix are health, education, livelihood, social and empowerment (WHO, 2010a). Each domain consists of several components. See Figure 1 for the CBR matrix. CBR programs try to offer access to facilities by making use of local resources. They are not obliged to offer access to all facilities themselves, however, they should be able to establish partnerships with other organizations in order to meet the needs. By networking with other agencies, CBR programs should be able to refer PWDs to facilities on all CBR domains (WHO, 2010a).

The first domain of the matrix, health, focuses on the right of PWDs to have access to "the highest attainable standard of health, without discrimination of disability" (WHO, 2010b). PWDs living in developing countries often lack access to basic health care and rehabilitation facilities, or cannot afford the costs of health care. CBR aims to increase the

level of health care facilities for PWDs, in order to ensure that the needs of PWDs and their families are addressed.

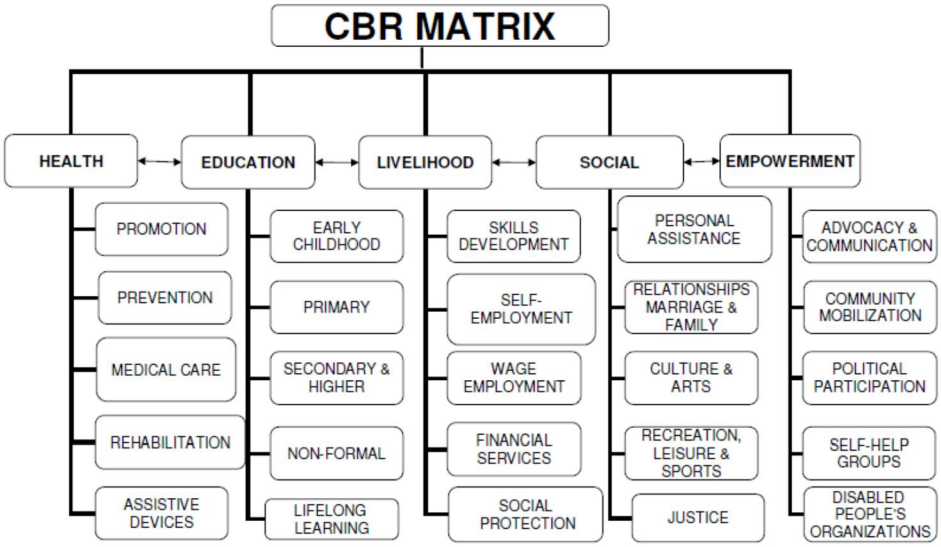

Figure 1 CBR matrix

The second domain, education, focuses on learning according to one's potential (WHO, 2010c). Learning can take place in the family, community or in school. The Convention on the Rights of Persons with Disabilities (CRPD) includes the right to inclusive education for PWDs. This access to education is essential, since a lack of education may lead to a risk of living in poverty and being excluded from the community. In practice, PWDs do not always have access to inclusive education, as a result of poverty and discrimination (WHO, 2010c). CBR strives to create inclusive education and to improve access to education for PWDs.

The third domain is the livelihood domain. As described above, poverty and disabilities are related. PWDs do not only experience difficulties because of poverty, but also experience other disadvantages, such as barriers to training, decent work or education (WHO, 2010d). Work is a way to escape poverty, and the right of PWDs to work is embedded in several conventions. In practice, PWDs often do not have possibilities to be employed (WHO,

2010d). The CBR strategy aspires to facilitate work for PWDs, since this increases their access to basic needs. CBR also aspires to enhance access to skills training, in order to offer access to livelihood opportunities, and to enhance participation in community life.

The fourth domain is the social domain. The personal development of PWDs is enhanced by including them in family and community life (WHO, 2010e). PWDs often have fewer opportunities to participate in social activities, than people without disabilities. Access to cultural activities, sports and recreation often is an exception, whereas this is important for PWDs (WHO, 2010e). CBR strives to enhance social roles and responsibilities of PWD, and to improve their access to social activities.

The last domain, empowerment, relates to the four other domains. The aim of CBR is to empower PWDs, their family and the community on the other domains by enhancing their confidence to ask for opportunities and to make use of opportunities (Velema & Cornielje, 2010). Another important aspect of empowerment is enhancing awareness of PWDs about their rights. People with disabilities, or parents of CWDs, can collaborate in Disabled People Organizations (DPOs) in order to claim their rights.

These five domains play a significant role in the CBR strategy and facilities on all domains should be included in the CBR facilitators' networks. This thesis focuses on the needs of children with physical disabilities, who specifically have needs on the domain of health. However, they also might have needs on the other domains. Since facilitators should be able to provide all needs of these children, the needs should be identified. Facilities that fit these needs, should be included in the facilitators' ideal network, in order to be able to provide in the needs of these children. Thus, what are the needs of these children and what should the ideal CBR facilitator's network look like? The first sub-question focuses hereon; "*What should the ideal CBR facilitator's network consist of, in order to provide in the needs of children with physical disabilities and their families?"*.

Explanations for the unavailability of facilities

The first sub-question of this thesis focuses on what the ideal facilitator's network should consists of, in order to provide the needs of children with physical disabilities and their families. However, it is possible that the facilitators' networks lack certain facilities, meaning they do not possess the ideal network. But how can this be explained? There are several factors known from literature which might influence what networks look like. These factors might be applicable on the CBR facilitators' networks.

To start with, the network of professional health workers is influenced by their knowledge on available new techniques and available facilities in the domain of health (Becker, 1970). It is important for these professionals to be up to date on the available facilities, since this enables them to refer people to these facilities and spread the knowledge on these facilities to others (Becker, 1970). Likewise, CBR facilitators should be up to date on the available facilities on the five CBR domains, in order to be able to spread this knowledge to the children and families they are counseling, and refer them to the facilities they need. Facilitators might differ in the degree in which they are up to date on available facilities on the five CBR domains, which might influence what their networks look like.

Further, differences between facilitators' networks might be caused by the presence or absence of interorganizational networks. Networks consisting of several organizations of different fields, are called interorganizational networks, and facilitators should aim to establish extended interorganizational networks, by staying in touch with schools, medical facilities and training centers, both inside and outside the community (Bailey & McNally Koney, 1996; ILO, UN, & WHO, 2004). Essential within these interorganizational networks is the collaboration between different actors, and facilitators knowing who are part of their interorganizational networks, since this may improve the facilitators' networks and the access to resources (Ihm, Shumate, Bello-Bravo, Atouba, Malick Ba, Dabire-Binso, & Pittendrigh,

2014). Thus, this leads to the hypothesis that facilitators who possess an interorganizational network, might be more likely to possess the ideal network.

Lastly, characteristics of the community might influence what social networks look like, since communities differ in the presence of facilities, and in the possibilities for community members to participate in activities (Cattell, 2001). The CBR facilitators' networks might be influenced by these community characteristics, since a lack of facilities in the community might cause difficulties for facilitators to refer children and their families to these facilities (ILO, UN, & WHO, 2004). Thus, facilitators who are working in communities with a lack of facilities, might experience difficulties in creating the ideal network.

All in all, available literature indicates there are factors that might influence what a network looks like, which might be applicable on the CBR facilitators' networks. However, it is unknown if the explanations for the unavailability of facilities according to CBR facilitators are in accordance with the available literature, or if they are providing other explanations. Thus, the current research strives to offer insight in explanations for the unavailability of facilities in the facilitators' networks, according to facilitators. The corresponding sub-question is *"What are the explanations for the unavailability of the needed facilities, according to CBR facilitators?"*. Before answering this sub-question, first the sub-question "*Which facilities are needed by children with physical disabilities and their families, but cannot always be provided by CBR facilitators?"* should be answered, in order to identify the unavailable facilities in the facilitators' networks.

Explanations for non-usage of facilities

As described above, there are factors influencing the availability of facilities in the CBR facilitators' networks. However, it is also possible that facilities are available in the facilitators' networks, nonetheless, PWDs and their families do not use these facilities. How can this be explained?

The available literature focuses mainly on explanations for not visiting health care facilities, in rural areas in developing countries. One of the most important explanations for not visiting available health care facilities, concerns the geographical distance to those facilities (Stock, 1983). Travel time to the health facilities is long, especially during the rainy season, which means that people have to travel a long time and might be arriving at a facility when it has already closed. Second, it turns out that people are willing to travel further for specialist care or quality care, than for public facilities (Stock, 1983; Halwindi, Siziya, Magnussen, & Olsen, 2013). Therefore, if regular health facilities are located far away, these facilities will not be visited regularly.

Further, parents are responsible for their children, and need to accompany their children when visiting health facilities (Stock, 1983). Parents are not always able to visit a facility with their child, as a result of the rainy season or planting season (Halwindi, Siziya, Magnussen, & Olsen, 2013). So if children are sick at an inconvenient moment and are in need of health facilities, their parents might be unable to accompany them, resulting in inability to visit the health facility. Lastly, facility usage depends on the costs of the facility (Halwindi, Siziya, Magnussen, & Olsen, 2013). Transportation might be expensive, however, facilities themselves can be rather expensive as well. In case families are living in poverty, they cannot afford the costs of the transportation and costs of the health facility.

Concluding, reasons for not visiting health facilities are related to the location of these facilities. The distance might be too long, and transportation costs might be too high. In addition, costs of the health facilities themselves are too high. However, these explanations mainly focus on health facilities. The CBR strategy also consists of other domains and facilities. What explanations do parents and children have for not visiting available facilities on the CBR domains? Are these explanations related to the costs and distance of the facilities, or are there other explanations? It might be relevant to gain insight in explanations for not

visiting available facilities, since these explanations should be taken into account when establishing and adjusting the facilitator's network. This should improve the facility usage by children and their families. The last sub-question of this thesis focuses hereon; "*Why do children with physical disabilities and their families not visit available facilities, while they do need them?"*.

Method

Current study

This study was conducted in the Philippines. The household population of the Philippines was 92,1 million in 2010 (Philippine Statistics Authority, n.d.). 1.6% of this household population was diagnosed with a disability. There are no official records on how many of these people with disabilities are diagnosed with a physical disability. However, according to a study conducted in 2008 in Metro Manilla, an urban setting, 32% of the respondents with disabilities was diagnosed with a physical disability (Tabuga & Mina, 2011). The same study is conducted in 2010 in Batangas, a rural setting, and almost 30% of the respondents with disabilities was diagnosed with a physical disability. People with physical disabilities were the second largest group in both studies.

The Philippines adopted several laws which were relevant for inclusion of people with disabilities, and founded the basis for the CBR strategy. First, the Magna Carta for Disabled Persons was accepted in 1991, and provides for "the rehabilitation, self-development and self-reliance of disabled persons and their integration into the mainstream of society and for other purposes" (Dandee, n.d.). Second, the government adopted Executive Order No. 437, which aimed to encourage the implementation of CBR for PWDs in the Philippines (Dandee, n.d.). This implies that all Local Government Units (LGUs) were allowed to adopt CBR programs in order to deliver facilities to PWDs, and to finance these programs.

One of the organizations providing training in CBR and monitoring organizations implementing CBR in the Philippines, is the NORFIL Foundation. Respondents included in this research were identified with help of the NORFIL Foundation. The NORFIL Foundation arranged the contact with their Partner Organizations that implement CBR. These Partner Organizations assessed which respondents were able to participate in this research.

Respondents

To conduct the research data, six NGOs that implement the CBR strategy in the Philippines were visited. All organizations were dependent on funds of international funding agencies. The organizations were located on different areas of the island of Luzon. Four of the organizations were located in the Bicol Region; some of them were partners and referred children to facilities of the other organizations. The fifth organization was located in Ilocos Sur, and the final organization in Manila. The size and composition of the organization varied. One organization consisted of only one facilitator, while another included over 20 facilitators. In addition, the organizations had varying background, some organizations were run by parents, while other organizations were run by social workers or other working professionals.

At each organization, semi-structured interview with CBR facilitators were conducted. At some organizations only one facilitators was interviewed, while at other organizations multiple facilitators were interviewed. In total, 15 CBR facilitators and one CBR team were included in this research. The CBR facilitators had different backgrounds, namely different work experience, educational backgrounds and they differed in (not) having a disability themselves or having a relative with a disability.

Furthermore, at each organization, five children and their families were visited to conduct semi-structured interviews with. Therefore, thirty children and their families participated in the research. All children had a physical disability and were of elementary school age (six till fourteen years old). Both the children, and the parents were allowed to

answer the questions during the interview. The children who participated suffered of various conditions, e.g. Cerebral Palsy, Congenital Deformities and Amputees, Cleft Palate, Osteogenesis Imperfecta, Hemiparesis, Pott's disease and Clubfoot. Some conditions were more severe than others.

Data collection

To identify the needs of children with physical disabilities and their families, semi-structured interviews were conducted. These semi-structured interviews consisted of background questions, e.g. the age of the child, the physical condition of the child and how long the child was included in the CBR program. Furthermore, the semi-structured interviews consisted of questions on the five CBR domains, in order to gain insight in the needs of the children and their families, and which facilities they were already visiting.

The interviews were based on the five domains of the CBR matrix, and were designed by making use of aspects of the Child Status Index (CSI) (Nyangara, O'Donnell, Murphy, & Nyberg, 2009). The Child Status Index is a tool that can be used to identify the needs of children on six domains, namely food/nutrition, shelter and care, protection, health care, psychosocial and education. These domains of the Child Status Index were compared to the five CBR domains, in order to identify which questions of the CSI suited the topics of the five CBR domains, and could be included in the interviews. The useful questions of the CSI were integrated with other questions based on the components of the five CBR domains. As a result, questions on the use of assistive devices, access to the PWD ID-card and participation of parents in Disabled Peoples Organizations (DPOs) were included. All together, the useful questions of the CSI and the questions based on the components of the CBR domains lead to the composition of the semi-structured interview as represented in Appendix A.

Both parents and children were allowed to answer the questions of the interview. However, in practice, parents answered most of the questions, since the children were shy or

unable to express themselves. When children did not visit available facilities, although they stated that they would like to visit the facility, the interviewers went into detail, in order to identify the reasons for not visiting these facilities.

Moreover, semi-structured interviews with CBR facilitators were conducted. The semi-structured interviews consisted of background questions, in order to gain insight in the characteristics of the facilitators. These questions focused on previous work experience of the facilitators, their education and the location of the organization they are working for. Furthermore, the interviews included questions on facilities that are part of the facilitator's network on the five CBR domains. First, the semi-structured interview for the children and their families was constructed, as described above. Afterwards, the semi-structured interview for children and their families was used to construct the facilitators' interview. The questions included in the facilitators' interview covered the needs that should be identified with the semi-structured interview for child and family. Thus, one of the questions from the semi-structured interview for children focused on their need for assistive devices. The accompanying facilitators' question focused on if facilitators were able to provide access to this facility. Furthermore, general questions on the facilities that facilitators can provide access to were included in the semi-structured interviews, in order to offer them the chance to mention other facilities that were included in their network. See appendix B for the semi-structured interview.

Before starting the interviews with both the facilitator and the child and family, the background of the research was explained, and participants were asked for informed consent. The respondents were informed about their rights and were informed that they were not obliged to participate in the research. The respondents were told that they could quit the interview at any time, and that they were not obliged to answer if they did not know, or did not want to answer.

Analysis

To answer the first sub-question about what the ideal facilitator's network should look like, the data of the semi-structured interview with the children and families was analyzed. During the interviews with the children and families, the needs of the children were processed in a visualized network. If parents and child perceived a facility as being located far away, the facility was visualized outside the large circle. If a facility was perceived as being located nearby, the facility was visualized within the large circle. See Figure 2.

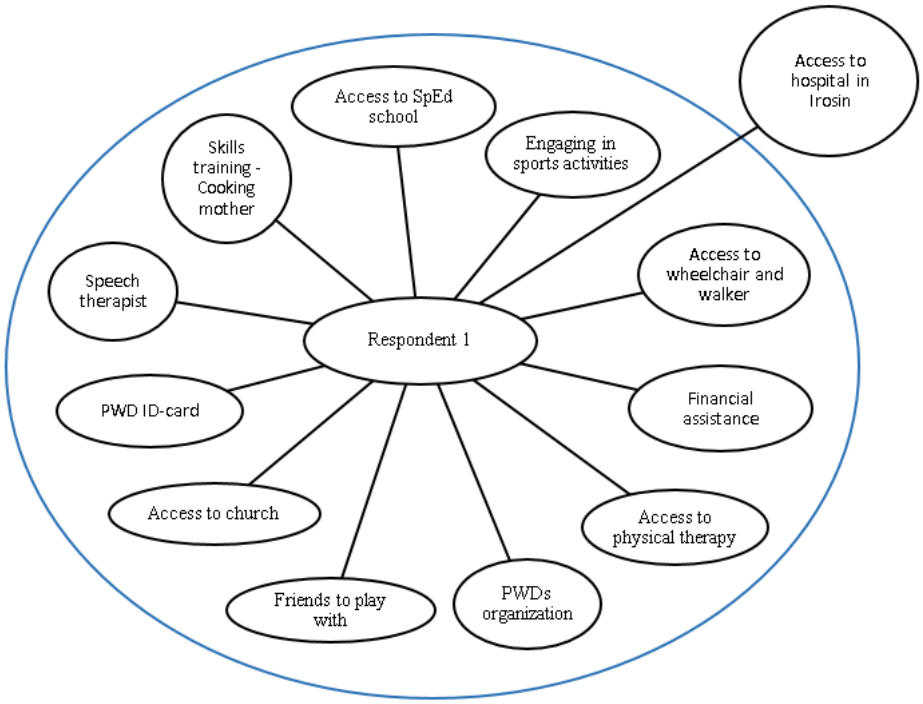

Figure 2 Visualized network respondent 1

In addition, five Excel sheets were created, in accordance with the five CBR domains. On each domain the mentioned needs were added to the Excel sheets, in order to identify what the needs of the respondents were. All facilities mentioned by at least one child were included in the ideal network, because facilitators should be able to provide all needs of the children. Furthermore, the facilities that cannot always be provided were analyzed, in order to answer the second sub-question, namely "*Which facilities are needed by children with physical disabilities and their families, but cannot always be provided by CBR facilitators?"*.

Firstly, it was analyzed how often children needed facilities, and how often facilitators were able to deliver facilities. This data was summarized in a table in which offered facilities are compared to needed facilities. This resulted in a table of how frequently facilities are needed and how frequently they can be offered. In order to summarize the data, categories on how often children need access to a facility, and how often facilitators can offer access to a facility were created. See Table 1 for an overview of how many times facilities have to be mentioned by children in order to be included in a certain category. See Table 2 for an overview of how many times facilities have to be offered in order to be included in a certain category.

Table 1
Categories of facilities depending on amount mentioned by child and family

Mentioned by child and family	Frequency mentioned
Rarely mentioned	0-10 times
Regularly mentioned	11-20 times
Often mentioned	21-30 times

Table 2
Categories of facilities depending on amount offered by facilitator

Offered by facilitator	Frequency available
Not available	0 times
Rarely available	1-8 times
Regularly available	9-15 times
Always available	16 times

Lastly, the two remaining sub-questions were analyzed. These sub-questions focus on explanations for the unavailability of needed facilities according to facilitators, and non-usage of available facilities according to children and their families. The given explanations were written down during the interviews. Afterwards, the explanations given for the unavailability of the facilities, or non-usage of facilities were processed in the already created Excel sheets under the corresponding CBR domain. After processing all explanations, the number of the

provided explanations were counted, and it was analyzed on which facilities the explanations were applicable. This data was used to answer the third and fourth sub-question.

Results

Ideal CBR facilitator network

The first sub-question focuses on the ideal facilitator's network according to children with physical disabilities and their families. The interviews provide insight into the needs of the respondents on the five CBR domains, see Table 3 for the overview.

Table 3
Needed facilities of children with a physical disability and their family on the CBR domains

Education	Health	Livelihood	Social	Empowerment
Daycare*	Check-up	Skills training	Sports	PWD ID-card
Elementary school	Hospital	Financial Assistance	Camp*	Parent Organization
	Physical therapy		Church	
Secondary school	Speech therapy	Microfinance	Socialization activities*	
Special education (elementary and secondary)	Assistive devices		Cultural activities	
	Occupational therapy*			

Note. Facilities marked with an asterisk (*) are not included in the further analysis since these facilities were identified during later child-interviews and it is unknown which facilitators are able to offer these facilities.

Table 3 contributes to an answer to the first sub-question *"What should the ideal CBR facilitator's network look like, according to the needs of children with physical disabilities and their families?"*. A facilitator with the ideal network should be able to refer children to regular schools or special education, both elementary and secondary level. On the domain of health, the CBR facilitator should be able to refer children to a place where they can get a

medical check-up, the hospital for specialist care, physical therapy, speech therapy and to organizations that offer assistive devices. On the domain of livelihood, facilitators should be able to refer children and their families to trainings for specific skills, microfinance providers, and financial assistance. This domain is followed by the social domain, which is important for PWDs, since they often are excluded from this domain. Facilitators who possess the ideal network for children with physical disabilities, should be able to refer them to sports and cultural activities, and church. Lastly, facilitators should be able to offer parents participation in Parent Organizations, and should be able to refer children to local government units, in order to perceive a PWD ID-card. This ID-card offers PWDs privileges and discounts on transportation, groceries and health care.

The availability of facilities in networks

The second sub-question is *"Which facilities are needed by children with physical disabilities and their families, but cannot always be provided by CBR facilitators?"*. As described in the analysis section, first how often facilities are mentioned by children and their families is identified, and how often facilitators are able to refer children to the facilities. The results are displayed in Table 4, in both amount mentioned and percentages.

Table 4
Needed facilities mentioned by children and family, and availability of facilities in exact amounts and percentages

Facility (Most to least mentioned by child and family)	Frequency facilities mentioned by children and family (N=30)	Frequency availability facilities in network facilitators (N=16)
Church	30 (100.0%)	16 (100.0%)
PWD ID-card	30 (100.0%)	16 (100.0%)
Parents organization	30 (100.0%)	15 (93.8%)
Financial assistance	27 (90.0%)	16 (100.0%)
Skills training	27 (90.0%)	14 (87.5%)
Cultural activities	26 (86.7%)	16 (100.0%)
Hospital	25 (83.3%)	16 (100.0%)
Sport activities	23 (76.7%)	16 (100.0%)
Physical therapy	23 (76.7%)	12 (75.0%)
Elementary school	19 (63.3%)	16 (100.0%)
Microfinance	19 (63.3%)	13 (81.2%)
Check-up	16 (53.3%)	15 (93.8%)
Assistive devices	15 (50.0%)	16 (100.0%)
Speech therapy	12 (40.0%)	9 (56.2%)
Special Elementary school	7 (23.3%)	14 (87.5%)
Secondary school	4 (13.3%)	16 (100.0%)
Special Secondary school	1 (3.3%)	9 (56.2%)

Table 5 summarizes which facilities are needed by children with physical disabilities and their families in relation to the facilitators' networks and indicates that all facilities are at least regularly available. The majority of facilities are always available and can always be offered to children, even when they are only rarely mentioned as a need. However, there are a few facilities which are not always accessible for the respondents. The answer to the third sub-question is that CBR facilitators cannot always provide access to physical therapy and skills training, while these facilities are often mentioned as a need by children and their families. Facilitators also cannot always provide access to medical check-up, speech therapy and microfinance. These facilities are regularly mentioned as a need of children and their

families. Lastly, access to special education, both elementary and secondary school, are rarely mentioned by children and their families, and cannot always be provided by facilitators.

Table 5
Need of facilities contrasted to availability of facilities

Availability of facilities				
	Unavailable	Rarely available	Regularly available	Always available
Rarely mentioned	-	-	Sped elementary Sped secondary	Secondary school
Regularly mentioned	-	-	Check-up Speech therapy Microfinance	Elementary School Assistive devices
Often mentioned	-	-	Physical Therapy Skills training	Hospital Financial Assistance Sport activities Cultural activities Church PWD-ID card Parent organization

Explanations for the unavailability of needed facilities

The third sub-questions seeks to find explanations for the unavailability of needed facilities according to facilitators. The focus will be on the facilities mentioned under the category 'regularly available', in Table 5. Table 6 indicates which explanations are provided by facilitators, and how often these explanations are mentioned by facilitators.

Table 6
Explanations for unavailability of needed facilities according to facilitators

Explanations (Most to least mentioned)	Frequency
There is a lack of therapists	11
Unavailable facility is the responsibility of the local government	6
The facilitator does not collaborate with other organizations	4
The facilitator does not know if the facility is available	4
The facility is included in regular schools	2

The lack of therapists is the most frequently mentioned explanation for the unavailability of facilities. This explanation is mentioned for the unavailability of speech therapy and physical therapy. Only 56% of the facilitators is able to offer children access to a speech therapist, and only 75% of the facilitators is able to refer children to physical therapy. There are only a few educated speech therapists in the Philippines, but they do not live in the regions where the facilitators are located. Physical therapists are also scarcely available in these regions.

The second explanation that focuses on the unavailability of facilities is the Local Government Unit's (LGU) responsibility for the establishment of facilities. This explanation is applicable to the unavailability of special elementary and special secondary education. If the LGU does not establish special education, the facilitators do not have any means to solve this. However, two facilitators mentioned that it is their task to lobby at the local government for the establishment of these schools. In practice, only one of them is actually lobbying for the establishment of the schools. Furthermore, there is one facilitator who is not able to refer children to a medical check-up, since there is no health center that offers the medical check-up in the community. The establishment of a health center is the responsibility of the LGU as well.

A third explanation is that facilitators are not collaborating with organizations in order to offer facilities they cannot offer themselves. This explanation is applicable on skills training. Two facilitators are unable to offer this facility and they mentioned that they are not collaborating with other organizations in order to offer skills training. The facilitator who was unable to refer children to a medical check-up did not collaborate with health centers in other regions. Lastly, there is one facilitator who is not able to offer microfinance, and is not collaborating with other organizations to offer this facility.

Fourth, facilitators lack the knowledge of a certain facility being available in their region. Two facilitators, who are unable to offer access to microfinance, explained this as a result of them not knowing where to find these agencies. In addition, two facilitators who cannot refer children to special secondary education indicated they do not know whether or not there is special education available and they did not try to find out if the schools exist.

The least mentioned explanation concerns the presence of special classes in regular schools. Two facilitators are not able to refer children to special secondary schools, however, they are able to refer children to special classes in regular schools. Consequently, children are able to attend special education, but only in regular schools.

The conclusion to the sub-question *"What are the explanations for the unavailability of needed facilities, according to CBR facilitators?"* is the unavailability of these facilities as a result of lacking educated therapists in the region. Other facilities are unavailable as a result of the local government not establishing them and, finally, facilitators sometimes are not informed on what facilities are available in their community, or do not cooperate with other organizations to offer these facilities.

Explanations for non-usage of available facilities

The fourth sub-question tries to explain why children and their families are not visiting available facilities while they do need them. Table 7 shows the explanations mentioned by children and families, and shows how frequent these explanations are mentioned.

The most frequently mentioned reason by children and parents for not visiting available facilities, is the geographical distance to these facilities. This reason can be divided into three components. The first problem with the distance to facilities is the cost of transportation. A lot of children with physical disabilities are unable to use public transport facilities, resulting in them being dependent on private transportation. Private transportation is more expensive than the public transport facilities, which makes it difficult for the children to

visit the facility. Also, the travel time to the facilities is long and parents are not always able to accompany their child to visit a facility.

Table 7
Explanations for non-usage of availability facilities according to child and family

Explanations (Most to least mentioned)	Frequency
Distance to facilities	13
Transportation costs	6
Travel time	5
Parents cannot accompany child	2
Child cannot participate because of disability	9
Hard to pay the loan for microfinance	6
Do not know about the existence of a facility	5
No time to visit a facility	4
Facility (building) is not accessible	3
Facility is too expensive	3

Another important reason for not visiting available facilities is that the condition of the child does not allow the child to participate. This is especially the case for social activities in the community, such as sports and cultural activities. Often, regular activities are available, but children cannot participate because of their disability. However, once or twice a year these children can participate in special sports and cultural festivities, specifically for children with disabilities. All children are able to participate in these activities, regardless of their disabilities.

Furthermore, parents often mentioned the need for microfinance. In practice, most facilitators are able to refer families to microfinance agencies, however, families do not go there. The main reason to not apply for microfinance, although they really need it, is the family's realization it might be difficult to pay the loan coming with these microfinance solutions.

Another explanation for not visiting available facilities is that families do not know about the existence of these facilities. This explanation is applicable to the use of the PWD

ID-card, which offers PWDs privileges such as a 20% discount on transportation and medical care. In practice, 20% of the children does not have this ID-card. Parents never heard about the ID-card and are unaware of the benefits the ID-card offers.

Lastly, there are a few explanations which are only mentioned three or four times. Firstly, parents sometimes do not have time to visit a facility like skills training, because they are too busy working or taking care of their children. The skills trainings are provided at set times, which results in some families being unable to visit the facility. Secondly, the accessibility of buildings can be a problem. A lot of buildings and facilities do not have ramps, resulting in children using a wheelchair being unable to enter the building. Lastly, the facilities themselves are sometimes too expensive. There are several expensive private facilities. This is specifically the case with speech therapy. Facilitators often know a private speech therapist, however, this is too expensive for the families, resulting in them being unable to ever visit the therapist.

The conclusion to the last sub-question *"Why do children with physical disabilities and their families not visit available facilities, while they do need them?"* is that there are several reasons for the non-usage of these needed facilities. Firstly, the distance to facilities, and the corresponding transportation costs and travel time, is one of the important reasons. Furthermore, children sometimes cannot participate because of their disability, the facility is too expensive, the facilities are not accessible, there is no time to visit the facilities, or there are no financial means to afford the loan coming with microfinance. Lastly, parents are sometimes unaware of the existence of a certain facility, even though they are available.

Remaining results

Adjacent to the results discussed above, there are more interesting results, which will be discussed in this section. During the interviews, multiple facilitators of four organizations

were interviewed about their networks. Table 8 gives an overview of their networks compared to the ideal network.

Table 8
Overview of how much the networks have in common with the ideal network in percentages

Facilitator	Percentage of ideal network
Organization 1	
Facilitator 1	94
Organization 2	
Facilitator 1	65
Facilitator 2	88
Facilitator 3	82
Facilitator 4	82
Facilitator 5	76
Organization 3	
Facilitator 1	100
Facilitator 2	89
Facilitator 3	100
Facilitator 4	100
Organization 4	
Facilitator 1	100
Organization 5	
Facilitator 1	100
Facilitator 2	100
Facilitator 3	89
Organization 4	
Facilitator 1	94
Facilitator 2	89

Table 8 indicates that the percentages of the ideal network are almost equal for facilitators who are employed for the same organization. The facilitators of organizations two and three almost all possess the ideal network, or only miss two facilities in their network, whereas the facilitators of organization one all do not possess the ideal network. The facilitators of organization four nearly possess the same percentage of the ideal network.

Conclusion and discussion

This thesis aimed to contribute to insights in the facilities CBR facilitators can offer to children with physical disabilities and their families. The thesis also contributes to knowledge

about factors that influence the availability and usage of facilities. The acquired insights can guide facilitators and the organizations that are working with CBR in improving their networks and enhance the availability and usage of facilities.

Regarding factors that seem to influence the availability of facilities in networks, facilitators explained they were unaware of the existence of certain facilities or there was a lack of specialized therapists. Furthermore, facilitators explained that the local government is not taking its responsibility for the establishment of certain facilities, and there is a lack of collaboration between organizations.

In addition, children and families explained they were not visiting facilities because of the geographical distance to facilities, and the corresponding transportation costs and travel time. Also, private facilities were the only available facilities, but they were too expensive, or facilities were inaccessible for the children. Moreover, often there was a lack of time to visit facilities or to participate in activities. Lastly, parents sometimes were unaware of the existence of facilities.

Implications of findings

The first sub-question contributed to an insight in what the ideal facilitator's network should look like in order to provide the needs of children with physical disabilities and their families. The practical implications of these findings may be significant, since it offers organizations and facilitators the chance to adjust and extend their networks conforming these needs, so they will be able to offer the needed facilities in the future. Furthermore, four facilities, namely daycare, occupational therapy, socialization activities and camp, were excluded from the research because it was unknown which facilitators were able to offer these facilities. Future research should include these facilities in order to identify facilitators who are able to provide these facilities, and in order to find explanations for the potential unavailability of these facilities.

Furthermore, this thesis focused on the availability of facilities. Speech therapy was not always available, and only 56% of the facilitators was able to offer access to this facility. Only 40% of the children needed this facility, however, most likely, the benefits of this facility will be significantly beneficial for them. Children diagnosed with Cerebral Palsy often experience difficulties in speech, and are unable to express themselves. Parents of these children emphasized the need for a speech therapist. So, even if facilities are only needed by a few children, the need for the facilities can be significant. The practical implication of this finding is that facilitators should lobby for more educated speech therapists, or should look for other means to offer speech therapy for these children, for example home-based speech therapy offered by teachers who are specialized in special education.

Additionally, the remaining results indicated that facilitators who are employed at the same organization, possess almost the same percentage of the ideal network. This indicates that the facilitators' networks might depend on the organizations they belong to. Moreover, it depends on the organization what amount of money is available, what their goals are and what kind of facilities the organization can offer. Consequently, in future research, it might be interesting to focus on the characteristics of organizations, in order to identify if organization characteristics are accountable for differences between networks.

Furthermore, this thesis aspired to find explanations for the unavailability of facilities in the facilitators' networks. Available literature on factors that influence the establishment of networks identified the facilitators' knowledge on available facilities and the lack of facilities in the community, as factors that influence the establishment of networks (Becker, 1970; Cattell, 2001). This thesis found the lack of knowledge on available facilities and the lack of facilities in the community as explanations for the unavailability of facilities, so the available literature on these factors seems to be relevant for the establishment of CBR facilitators' networks. Furthermore, available literature focuses on the importance of the establishment of

interorganizational networks and the collaboration with other organizations (Bailey & McNally Koney, 1996). This thesis identified that a lack of cooperation between facilitators and organizations is an explanation for the unavailability of facilities, so this seems to be in compliance with the available literature. However, this thesis did not focus on the presence of an interorganizational network, thus future research should focus on this aspect, in order to identify whether an interorganizational network with several actors increases the access to resources. Lastly, explanations are found that are not discussed in available literature yet, namely a lack of specialized therapists, a lack of responsibility of the Local Government for the establishment of facilities, and the inclusion of special education in regular schools. These findings provide more insight in possible explanations for the unavailability of facilities, which were unexplored in literature before, so these findings complete the already available literature. The explanations found might be theoretically relevant, since they were unexplored in literature before and offer new insights in factors that influence the establishment of networks.

Additionally, the practical implications of the findings on the unavailability of facilities are that the organizations and facilitators can take these factors into account, in order to improve their networks. Facilitators sometimes were unaware of the existence of certain facilities, which should be improved by educating them. Further, there was a lack of collaboration between organizations, which caused an inadequate network. Facilitators and organizations should strive to partner with other organizations, in order to enhance their networks. Additionally, the lack of responsibility at the local government is an important explanation, which should be taken into account. Facilitators and organizations should lobby at the local government to improve their responsibility. Lastly, the theoretical implication of these findings is the contribution to an insight in possible factors that might be essential in the

establishment of networks, since there is limited to none literature available on possible factors that might be essential in the establishment of networks.

Moreover, as described in the introduction, explanations for not visiting available health facilities were related to the distance of facilities, the costs of transportation and a lack of time. The findings of this research were congruent with these explanations, and are applicable on all CBR domains. Furthermore, other explanations were found, such as the accessibility of buildings where facilities are located, or parents who were not aware of the existence of facilities. However, the information provision about facilities is the responsibility of facilitators, so a lack of knowledge of the parents correlates with a lack of information provided by the facilitator. These findings contributed to a more comprehensive overview of explanations that are related to the non-usage of available facilities available in literature, since there were other explanations found than what was already known. Thus, the theoretical implications of these findings are the adjustment to the already available literature on this subject. The practical implications of these findings are that the accessibility of buildings should be improved, and children should be assisted more in participating in activities, in order to enhance the facility usage.

Strengths and limitations of the research

This thesis provided insight in factors that play an essential role in the availability and usage of facilities. A strength of this research is the contribution to improving the insight in explanations for the unavailability and non-usage of facilities, since there is limited to none literature available on these topics and the founded explanations might be relevant to take into account when establishing a network.

However, there also are some limitations. To start with, the facilitators were employed at organizations sponsored by the NORFIL Foundation and the Liliane Foundation. Since the researchers were related to these organizations, there was an improved chance of getting

socially desirable answers. Likewise, there was an improved chance of getting socially desirable answers from children and their families, since the facilitators who function as translators, were affiliated to the organizations. Children and their families might not want to offend the facilitator and organization with the answers they provided. In addition, the level of the facilitators who translated was not always sufficient. Because of this, the translation of the questions and answers were less reliable than preferred. Furthermore, the translators could influence the translations in their own interests, so there is a possibility the provided answers were distorted or incomplete.

Furthermore, the interpretation of the findings should be interpreted with caution, since the findings are based on interviews with a small group of respondents. In order to be able to draw a more meaningful conclusion on the findings, future research should focus on the same factors as this research, and include a larger group of respondents.

Additionally, the researchers were not able to select the respondents at random, since the NORFIL Foundation selected the organizations that were participating. The criteria on which these organizations were selected are unknown. However, their backgrounds, compositions and methods were different, so diversity was taken into account. In addition, the organizations selected the children who were participating in the research, resulting in the children not being randomly selected, either. Further, the findings of the research might not be generalizable, since the organizations were all located on the Island of Luzon, thus within one region in the Philippines. In addition, the findings might not be generalizable to other countries that implement the CBR strategy. However, it would be interesting to take the findings of this research into account when exploring the facilitators' networks in other countries, in order to identify if the findings are generally applicable.

Despite the limitations of this research, it has some strengths. Firstly, it contributed to both the literature on CBR, and it provides insight in factors that might influence the

establishment of networks' and the usage of facilities. Another important strength is the variation is conditions of the children that participated in the research. As a result of this variation, the research gained insight in the needs of children with different kinds of physical disabilities, so that the identified needs of the research probably contain all possible needs of this target audience. Lastly, the practical implications of the acquired data is important, especially for the CBR program in the Philippines.

Conclusion

The main question of this thesis was "*Which factors play a role in the availability and usage of facilities for children with physical disabilities and their families?"*. To start with, the availability of facilities is influenced by the knowledge of facilitators on available facilities, the responsibility the local government takes in establishing facilities, the availability of specialized therapists and the collaboration between organizations. Further, the usage of facilities is influenced by the geographical distance to facilities, the corresponding transportation costs and travel time, the accessibility of facilities, and the knowledge of parents on the existence of facilities. Thus, there are several factors that should be taken into account when establishing a network that matches the needs of the children and their families. All in all, in practice, the facilitators' networks exist of several facilities, and mostly correspond with the needs of the children with physical disabilities. However, progress still should be made when it comes to facilities that are included in the networks and facility usage by children and their families, by taking the discovered factors into consideration.

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Appendix A. Semi-structured interview child and parents

1. What is your name?
2. How old are you?
3. Since when are you included in the CBR program?
4. Why did you join the CBR program?

Specific questions about the needs of the children; which facilities do they already visit and which facilities do they wish to visit? Where is everything located? Why is a child not visiting a specific facility if he needs it?

Education

- Are you going to school? Where?
- Is school easy accessible to you?
- Can you participate in all subject?
- How is your performance in school?
- Do you have any needs on the domain of education?

Health

- Which health care facilities are you visiting? Where are they located?
- Do you visit physical therapy? Do you need it?
- Do you receive speech therapy? Do you need it?
- Do you use any assistive devices? Do you need it?
- Do you need to visit any other health care facility?

Livelihood

- Did you receive skills training? Do you need skills training?
- Do you receive financial support from the program? Do you need it?
- Do you receive microfinance? Do you need it?
- Do you have any other needs on the domain of livelihood?

Social

- Do you participate in sport activities? Do you need/want to participate?
- Do you participate in cultural activities? Do you need/want to participate?
- Are you going to church? Is it easy accessible?
- Do you have any other needs on this domain?

Empowerment

- Are you member of a self-help group or Parent Organization? Where is it located?
- Are you satisfied with the level of awareness on disabilities in the barangay?
- Do you have the PWD ID-card?

Final question to the child: What do you want to become when you grow up?

Appendix B. Semi-structured interview CBR facilitator

1. What is your name?
2. How old are you?
3. Sex?
4. How long are you working as CBR facilitator now?
5. Which education/training did you follow?
6. What is your previous work experience?
7. Are you volunteer or paid employee?
8. Do you yourself or someone in your family have a disability?
9. Rural/urban environment?

Which facilities are part of the network of the facilitator? Is he able to provide the facilities on the five CBR domains?

Education

- Which schools can you refer children to? Elementary/secondary/special education?

Health

- Which health care facilities can you offer?
- Can you offer speech therapy?
- Can you offer physical therapy?
- Can you offer assistive devices?
- Do you have a hospital in your network?
- Do you have any health care center (barangay/rural health center) in your network?
- Can you refer children to a medical check-up?

Livelihood

- Can you offer skills training? Do you offer it yourself or do you refer people to other organizations?
- Are you able to offer financial assistance? Can you refer people to agencies that can offer this assistance?
- Do you have any microfinance agencies in your network?

Social

- Do you know if there are sport activities in the barangay? Do you organize activities for PWDs?
- Do you know if there are cultural activities in the barangay? Do you organize activities for PWDs?
- Do you have a church in your network?

Empowerment

- Can you help parents to participate in a Parents Organization? Do you know where to find Parents Organizations?
- Do you do something to create awareness on disabilities?
- Do you know where to arrange the PWD ID-card?

Appendix C. Informed consent form for CBR facilitators

Informed consent form for CBR field staff

Concerning the study*: "Community Based Rehabilitation (CBR) in the Philippines; which characteristics, approach and network lead to accurate identification of and provision in needs of children with disabilities and their families"*

Dear participant,

In this interview we would like to talk with you about the way you identify needs of children and families and your network.
This interview will be part of a study which explores CBR facilitator characteristics, approach to needs assessments and network to provide in needs of children with disabilities and their families.

During the interview Lynn van Duurling and Lizzy Hutten will be present. Your involvement in this research is voluntarily. You may withdraw from this research project at any time by giving a written or spoken notice. You are not obliged to give any reason for wanting to be left out of this research project. With your permission, the interview will be audio recorded. The audio recording is to accurately record the information you provide, and will only be used for transcription. The audio tape will be erased after transcription. We will not provide any incentive for your participation in this interview. All your provided information will be treated confidentially and will be processed anonymously.

I hereby declare that:

- I have understood everything from this consent form.
- I am willing to participate in this interview.

Name participant: Name interviewer:

…… …….

Signature participant: Signature interviewer:

…… …….

Date:

……

Appendix D. Informed consent form Child and Family

Informed consent form for Child and Family

Concerning the study*: "Community Based Rehabilitation (CBR) in the Philippines; which characteristics, approach and network lead to accurate identification of and provision in needs of children with disabilities and their families"*

Dear Parent/Caretaker,

In this interview we would like to talk with you and your child about the needs of your child and the provided facilities by the program your child is involved in.
This interview will be part of a study which explores CBR facilitator characteristics, approach to needs assessments, and network to provide in needs of children with disabilities and their families.

During the interview Lynn van Duurling and Lizzy Hutten will be present. Your involvement in this research is voluntarily. You and your child may withdraw from this research project at any time by giving a written or spoken notice. You are not obliged to give any reason for wanting to be left out of this research project. With your permission, the interview will be audio recorded. The audio recording is to accurately record the information you provide, and will only be used for transcription. The audio tape will be erased after transcription. We will not provide any incentive for your participation in this interview. All your provided information will be treated confidentially and will be processed anonymously.

I hereby declare that:

- I have understood everything from this consent form.
- I am willing to participate in this interview.

Name participant: Name interviewer:

…… …….

Signature participant: Signature interviewer:

…… …….

Date:

.....

Appendix E. Research Permission Letter

Research permission letter

I grant Lynn van Duurling and Lizzy Hutten permission to conduct research at (name organization):_____

The research concerns the characteristics and network of CBR facilitators in identifying and providing in the needs of children with disabilities and their families.

This research is part of the Master's Thesis' of Lynn van Duurling and Lizzy Hutten, students from Utrecht University, The Netherlands. The research is supervised by Utrecht University and the Liliane Foundation. The final reports will be send to the participating programmes.

I approve the following research methods to be used:

□ Interview with CBR faciliators

□ Interview with children/families

Name: Date:

Position: Signature: