



JÖNKÖPING UNIVERSITY

*School of Health and Welfare*

# Children with Intellectual Disabilities and Their Perceived Participation in Everyday Life Activities

A descriptive study conducted in Addis Abeba, Ethiopia

**MAIN SUBJECT:** *Occupational therapy*

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## Summary

**Background:** Children with intellectual disabilities living in developing countries are vulnerable to participation restrictions. Few studies have been made regarding their own perspectives. **Aim:** To describe how children in a low income country aged 13-17 with an intellectual disability perceive their participation in everyday life activities. **Method:** This bachelor thesis was conducted as a descriptive study and had a quantitative approach. Participants were collected through a non-probability, goal-oriented consecutive sampling. Data were collected by using “Picture my Participation”, an instrument designed as a structured interview with quantitative questions. The data were analyzed with IBM SPSS Statistics 21. Tables and diagrams were made in Microsoft Excel 2013. **Result:** The activity that the children participated in most frequently was “Daily routines at home for personal care (dressing, choosing clothing, hair care, brushing teeth)”. The activity that most children prioritized as most important, and they were most involved in was “Organised leisure activities”. “Services and policies” and “Social environment” were the factors seen as “Facilitators” to participation, whereas “Family attitudes” was seen as a “Barrier” to participation. **Conclusion:** The children perceived their participation in the prioritized activities as high and experienced few barriers in the context of participation.

**Keywords:** Adolescents, Disabilities, Low income country, Occupational therapy, Picture my Participation

## Sammanfattning

**Titel:** Barn med intellektuella funktionsnedsättningar och deras upplevda delaktighet i dagliga aktiviteter. En deskriptiv studie genomförd i Addis Ababa, Etiopien.

**Bakgrund:** Barn med intellektuella funktionsnedsättningar som lever i utvecklingsländer är sårbara för delaktighetsinskränkningar. Få studier har gjorts som rör deras perspektiv. **Syfte:** Att beskriva hur barn i ett låginkomstland mellan 13-17 år med en intellektuell funktionsnedsättning upplever sin delaktighet i dagliga aktiviteter. **Metod:** Kandidatuppsatsen genomfördes som en deskriptiv studie med en kvantitativ ansats. Deltagare samlades in genom ett icke-slumpmässigt-, målinriktat konsekutivt urval. Data samlades in med "Picture my Participation", ett instrument designat som en strukturerad intervju med kvantitativa frågor. Data analyserades i IBM SPSS Statistics 21. Tabeller samt diagram gjordes i Microsoft Excel 2013. **Resultat:** Aktiviteten som barnen deltog mest frekvent i var "Daily routines at home for personal care (dressing, choosing clothing, hair care, brushing teeth)". Aktiviteten som flest barn prioriterade som viktigast, och var mest involverade i var "Organised leisure activities". "Services and policies" och "Social environment" var faktorer som sågs som "Facilitators" till delaktighet, medan "Family attitudes" sågs som en "Barrier" till delaktighet. **Slutsats:** Barnen upplevde en hög delaktighet i de prioriterade aktiviteterna och upplevde få barriärer i relation till delaktighet.

**Nyckelord:** Arbetsterapi, Funktionsnedsättning, Låginkomstland, Picture my Participation, Ungdomar

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## Introduction

As a group children with disabilities are particularly vulnerable to participation restrictions, due to problems in the interaction between the child and its social and physical environment (Harding et al., 2009). Intellectual disability restricts participation in activities in everyday life, for example engaging in leisure activities (Arvidsson, Granlund, Thyberg & Thyberg, 2013). Children with disabilities have less support from the environment in the society, are less involved, and do not participate in activities as often as other children (Bedell et al., 2013). To participate in activities outside of school is vital when it comes to the promotion of the child's development of social relationships, essential skills and competencies, as well as the mental and physical health and well-being. A low degree of participation in childhood correlates with low life satisfaction in the future (Harding et al., 2009).

According to Lyngnegård, Donohue, Bornman, Granlund and Huus (2013) very few studies have focused on children living in low and middle income countries [LMICs], their own perspective and how they perceive their life situation, therefore this kind of research is needed. Harding et al. (2009) also address the importance of mediating the children's own perspectives, since they often differ from the perceptions and concerns of the adults. Furthermore, Hammarlund (2015) argues the need and interest of further research about children living with a disability in a low or middle income country and their own perspectives. United Nations [UN] (1989) article number 12 in the Convention on the Rights of the Child [CRC] clearly states that all children have a right to express their opinion and view regarding all matters concerning them. The authors of this bachelor thesis believe that more research within the area is necessary to gain additional knowledge about the subject. Furthermore, the authors' ambition is that this bachelor thesis will contribute to future research within the area which hopefully will lead to more knowledge about how children with intellectual disabilities perceive their own participation. This knowledge is important to occupational therapists and the society in order to be able to work with this group in terms of social inclusion. By working with social inclusion people with an intellectual disability could be integrated into the society in various forms of employment, education and health care. This could, in turn, lead to a decreased level of poverty among people with intellectual disabilities.

## Background

According to the World Health Organization [WHO] (2014) Ethiopia is listed as a low-income country, where 30,7 % of the inhabitants live on less than one USD per day. The life expectancy in Ethiopia is 62 years for males and 65 years for females (WHO, 2014). Ethiopia is the third most populated country in Africa (WHO, 2013) with approximately 91,729,000 inhabitants (WHO, 2012) where 50 % of the population is aged under 18 (WHO, 2011a). The Ethiopian health care sector faces several challenges, partly due to insufficient funding, a shortage of the workforce that is required and a weak implementation capacity. These challenges include a low prevention of diseases that are transmitted from mother to child and high rates of neonatal and maternal deaths (WHO, 2013). There are no education institutions for occupational therapists in Ethiopia (Béguin, 2013) and 88% of all occupational therapy services are given by non-governmental organizations (The African Child Policy Forum [ACPF], 2011).

Eighty-five percent of all children with a disability live in developing countries (Maloni et al., 2010) and the access to suitable interventions for children with disabilities are often limited in LMICs (Daley, Singhal & Krishnamurthy, 2013). Children with disabilities are disadvantaged when it comes to access to rehabilitation and, less than 5 % of these children have access to rehabilitation services (Lyngnegård et al., 2013; Maloni et al., 2010). Reasons for this may be that intervention of this kind does not exist in the country or that requests for interventions exceed the existing services capacity (Daley et al., 2013). Lyngnegård et al. (2013) describe that about 200 million children under the age of five who live in Asia and Africa do not reach their full cognitive potential due to malnutrition, poor health, and economic disadvantage. According to ACPF (2011) special care services are not common in Ethiopia, especially not different types of rehabilitation. Rehabilitation does not get prioritized because healthcare gets over encumbered by HIV and AIDS care. Other factors that influences the opportunities for rehabilitation are the access to healthcare and the cost of the services provided (ACPF, 2011).

Studies have shown that there is a correlation between the presence of poverty and disability, where poverty is a reason for an increased amount of people with disabilities. Poverty increases the occurrence of disabilities in the form of limitations to information, healthcare and clean water. Poverty is not only the cause but also a consequence of disability because of social norms that exists in the society. These norms create a grouping where children with a disability have a larger risk of becoming poor than children without a disability (ACPF, 2011). Furthermore, a link between the parents' educational level, household income, the geographical site, and the child's participation has been found (Harding et al., 2009). WHO (2011b) also confirms the correlation between poverty and disability. When children with a disability are not guaranteed education, they will less likely be able to get employment. Furthermore, a disability often results in the need of aids, healthcare and assistance.

According to Arvidsson et al. (2013) intellectual disability is defined as a multifaceted state which is established during the developmental period. David et al. (2014) describes that it is common that intellectual disabilities are inherited, as well as connected to socioeconomic status. According to Pendzick and Demi, (2009) the definition of intellectual and developmental disabilities has changed over time. Earlier the intellectual impairment was described by using the terms mild, moderate, severe and profound but now it is described in correlation to the amount of support that is needed to be able to function in everyday life. An intellectual disability involves limitations in the intellectual functioning and adaptive behavior. These limitations can be shown in forms of reduced memory, slow learning and attention deficits. It may also include difficulties in knowing how to begin and proceed in different tasks, use tools in different tasks, communicating, abstract thinking, judgment, and problem solving. Difficulties in adaptive behavior, such as making decisions on what to wear and eat, stem from problems using conceptual, social and practical skills that are needed to function in everyday life (Pendzick & Demi, 2009).

An activity is everything a person does within the social, physical, cultural, societal and time-bound contexts in life (Kielhofner, 2008). The International Classification of Functioning Disability and Health [ICF] defines activity as “the execution of a task or action by an individual” and participation is defined as “the involvement in a life situation”. People may experience participation restrictions if they are experiencing problems in involvement in different life situations and activity limitations if they are experiencing difficulties in executing

activities (WHO, 2001). Participation in everyday occupations is an important part of life and human development (Law, 2002).

Model Of Human Occupation [MOHO] describes that the three components volition, habituation and performance capacity affect a person's ability to participate in activity. These components involve how people choose, organize and perform certain activities. A person's participation in occupation is also affected by environmental factors, such as the surrounding physical and social environment. The environment, in turn, is shaped and defined by culture, which restricts or enables a person to participate in activities. Occupational participation is when a person gets involved in activities that they want to perform as well as necessary activities that they have to perform in order to reach a feeling of well-being (Kielhofner, 2008). Through occupational participation a person develop skills, socialize with other people and find meaning in life (Law, 2002).

Intellectual disability restricts participation in activities in everyday life, for example engaging in leisure activities (Arvidsson et al., 2013). Furthermore, children with a disability participate in less recreational activities, tasks in the household and social engagements or activities. Research points out that participation changes when children become older and the amount of activities that take place outside of the home decreases (Law, 2002). Article number 23 in the CRC describes that all children with any kind of disability have the right to participate in society and live a full and decent life (UN, 1989) and according to United Nations Children's Fund [UNICEF] (2005) CRC has been ratified by Ethiopia. Furthermore, article number three in the Convention on the Rights of Persons with Disabilities [CRPD] states that persons with disabilities should have the right to inclusion and participation in the society (UN, 2006).

In LMICs it is common to have a view of disability as something temporary. Parents might be under the impression that witchcraft is the cause of the child's disability and often try to find ways to cure their child and make him or her like the other children. It is also a common belief in the community that children with disabilities are embarrassing, shameful and should not be shown to other people (Lyngnegård et al., 2013). Article number two in the CRC clearly states that no child should experience any kind of discrimination, regardless of disability status, or for any other reason (UN, 1989). Despite this, the cultural beliefs held by parents and the community can contribute to loneliness and isolation among children with disabilities (Lyngnegård et al., 2013), as well as marginalization and second-class citizenship in the form of exclusion from socioeconomic life and education (ACPF, 2011).

Children with disabilities are not as frequently involved in research as children without disabilities. Researchers believe that these children have a lot to contribute with by expressing their views and opinions on different areas in life (Bailey, Broddy, Briscoe & Morris, 2014) in order to affect the social context they are a part of (Irwin & Johnson, 2005). Historically, the parent has worked as the voice of the child in research, which has led to an incomplete picture of the child's perspective since the parent's perceptions rarely correlate with the child's. By investigating the children's own perspective, a better understanding about their health can be developed (Irwin & Johnson, 2005). Furthermore, article number seven in the CRPD describes that children with disabilities have the right to express their opinions and views freely regarding all matters concerning them (UN, 2006).

## **Aim**

The aim was to describe how children in a low income country aged 13-17 with an intellectual disability perceive their participation in everyday life activities.

## **Questions**

- Which activities did the children participate in most frequently?
- Which activities did the children prioritize as most important?
- How involved were the children in the prioritized activities?
- Which were the facilitators or barriers affecting the children's participation in activities?



## Method

### Study design

This bachelor thesis was performed at a center for children with intellectual disabilities in Addis Abeba, Ethiopia. This thesis had a quantitative approach (Kristensson, 2014) and was conducted by using the instrument “Picture my Participation” (UNICEF in prep, see appendix 1), an instrument designed as a structured interview with quantitative questions. This thesis investigated the children’s perceived participation in everyday life activities. According to Kristensson (2014) this kind of study is as a descriptive study where the aim is not to search for a relationship between different variables, but instead to simply describe the occurrence of variables.

The method of selection that was used was non-probability, goal-oriented, consecutive sampling. Consecutive sampling is characterized by continuously asking individuals who are present in a specific context to participate. This continues until a sufficient amount of participants are collected. The consecutive sampling is a good method of selection since the authors are allowed to ask individuals to participate both before and during the data collection, which contributes to a representative sample (Kristensson, 2014).

### Participants

The children at the center in Addis Abeba, Ethiopia, have different types and degrees of intellectual disabilities. They have limitations in the area of intellectual functioning, their intelligence is below average, and they have a decreased ability to learn, as well as difficulties with decision-making and problem solving. The children also have different degrees of limitations in the area of adaptive behavior, for example not being able to communicate effectively, difficulties interacting with others, and problems managing activities of daily living. Regardless of their limitations, the children are capable of communicating on their own level (A. Mekonnen, personal communication, December 6, 2015).

The sample was collected from the center. Service users were asked to participate in the interview. This bachelor thesis had 18 participants including ten females and eight males. The participants were between the ages of 13-17 (see table 1) and had a mean age of 15 years. The children had the ability to express themselves, with words and/or pictures and had to give their assent to participate in the interview. Since the children were under the age of 18 a parent of the child also had to give consent for participation in the interview. This bachelor thesis had a total of two non-responses, one of them due to that the parent/s did not sign the consent form and the other one due to not being able to participate in the interview since he/she was non-verbal.

Table 1. Distribution of age and gender among the participants (n=18)

Age	Female	Male	Total
13	2	0	2
14	5	2	7
15	2	1	3
16	0	3	3
17	1	2	3
Total	10	8	18

## Data collection

### ***Instrument***

Data were gathered using an instrument called “Picture my Participation” which is under development by UNICEF (Willis, Imms, Granlund, Bornman & Elliott, 2015). This instrument was developed for children who have a disability and are between the ages of 5-17 (UNICEF in prep, see appendix 1). With the help of pictures it was possible to perceive the occurrence and involvement regarding participation in home, community and school situations. The possibility to examine barriers and facilitators regarding participation was also given (Willis et al., 2015).

The instrument consists of five steps:

1. An introduction about the instrument was given to the child, and its parent/parents if they were present. The test leader informed the participant about the aim of the interview, as well as what kind of questions that would be asked. The test leader also informed the child that there was no right or wrong answer (UNICEF in prep, see appendix 1).
2. Information was collected about the frequency of involvement. With the help of pictures the child was asked to show which of the 19 activities presented in the instrument that he or she participated in and how often by using a frequency table with six possible alternatives for answering (“Always”, “Sometimes”, “Not really”, “Never”, “N/A” and “Unsure or no answer”) (UNICEF in prep, see appendix 1). The meanings of the different alternatives for answering are defined in Table 2.

Table 2. Definitions of the alternatives for answering in the category “Frequency of involvement”

<b>Score</b>	<b>Level</b>	<b>Definition</b>
6	Always	The child participates all of the time
5	Sometimes	The child participates some of the time
4	Not really	The child occasionally/rarely participates
3	Never	The child does not participate
2	N/A	Not relevant to the child
1	Unsure or no answer	The child does not know the answer or does not answer at all

3. The child was asked to prioritize the three most important activities and put the pictures representing them together in a pile (UNICEF in prep, see appendix 1).
4. The child was asked about his or her level of involvement regarding the three prioritized activities. The child was asked to rate the level of involvement in each of the three activities by putting the pictures on the “level of involvement table” which had five possible alternatives for answering (“Very”, “Somewhat”, “Not”, “N/A” or “Unsure or no answer”) (UNICEF in prep, see appendix 1). The meanings of the different alternatives for answering are defined in Table 3.

Table 3. Definitions of the alternatives for answering in the category “Level of involvement”

<b>Score</b>	<b>Level</b>	<b>Definition</b>
5	Very involved	Generally, the child is engaged throughout the activity. He or she shows a lot of initiative and/or interest in and attention to what he or she and others are doing during the activity.
4	Somewhat involved	The child is engaged in the activity some of the time. He or she shows some initiative and/or interest in and attention to what he or she and others are doing during the activity.
3	Not involved	Child is engaged in a small part of the activity. He or she only shows a little initiative and/or interest in and attention to what he or she and others are doing during the activity.
2	N/A	Not relevant to the child
1	Unsure or no answer	The child does not know the answer or does not answer at all

5. The last step of the instrument involved barriers and facilitators regarding environmental and personal factors. The child was asked to think about one of the three prioritized activities at a time and consider if any of the five factors presented (“Services and policies”, “Physical”, “Social- support/relationships, products/technology”, “Attitudes- Your family, Your community, friends and neighbors, Beliefs/value systems of society” and “Who you are?”) enabled or restricted participation in the specific activity. The possible alternatives for answering were “Facilitator (easier)”, “Barrier (harder)”, “Neutral” and “N/A” (UNICEF in prep, see appendix 1). The meanings of the different alternatives for answering are defined in Table 4.

Table 4. Definitions of the alternatives for answering in the category “Barriers and Facilitators”

<b>Score</b>	<b>Level</b>	<b>Definition</b>
5	Facilitator (easier)	Anything that helps the child to participate
4	Barrier (harder)	Anything that makes it harder for the child to participate
3	Neutral	It does not make it easier or harder
2	N/A	Not relevant to the child

### ***Procedure***

1. Contact was taken with the coordinator of the center with the purpose to get advice about how to contact the needed participants. The authors were advised to ask the responsible teacher in each class about names of children within the stipulated age range. A total of 20 names were collected from six different classes. The teachers contacted the parents of the children whose names had been collected and asked them to come to the center to get information about the thesis and sign a consent form.
2. An interpreter was used to translate information letters and consent forms from English to Amharic. Another interpreter translated the documents back to English to make sure that the translation was made correctly. A separate information letter about

the thesis was developed for each party, one for the coordinator (see appendix 2), one for the participants (see appendix 3) and one for the parent/s (see appendix 4).

3. At the center the participants and their parent/s received the information letter about the thesis, the instrument that was going to be used and that they had to give their consent/assent prior to data collection. The consent form was developed so that both the children who had the ability to write and those who did not could give their assent. For those children who did not have the ability to write the opportunity to give oral assent instead of written was given on the consent form. Pictures with the symbols for “yes” and “no” were used to enable the children who could not write to give an oral assent (see appendix 5). The opportunity to sign the consent form was also given to the remaining children and the parent/s (see appendix 5). The consent form gave the participants information regarding their rights while participating in the thesis. The forms were signed by the children and their parent/s and collected for safekeeping. A total of 19 consent forms were collected, hence one external drop out was noted at this step.
4. The children who choose to participate were brought from their classroom once it was time for the interview. The interviews were conducted at the center in a separate room with one participant at a time. The interviews were performed with the interview schedule of Picture my Participation (UNICEF in prep, see appendix 1) as a guide. Both of the authors were present during all of the interviews. One of the authors conducted the interview while the other author recorded the numbers that corresponded with the child’s answers on the scoring sheets (see appendix 6). The authors of this bachelor thesis conducted interviews with a total of 18 children, nine children each. Additionally, one external drop out was noted at this step, hence a total of two external drop-outs were noted in this thesis. An interpreter was used due to the language barrier and translated between English and Amharic.
5. Finally, the scoring sheet of the instrument (see appendix 6) was used to compile the collected data. The analysis program IBM SPSS Statistics 21 (Wahlgren, 2012) was used to analyze the data and Microsoft Excel 2013 was used to create tables and diagrams. This is described further down under “data analysis”.

### ***Validity and Reliability***

Picture my Participation is under development by UNICEF and is currently being tested for validity and reliability (Willis et al., 2015).

### **Data analysis**

The data were analyzed on the basis of “Picture my Participation” (UNICEF in prep, see appendix 1) and its scoring appendix (see appendix 6). With the result from the interviews it was possible to distinguish the children’s frequency and level of involvement, but also if there were any facilitators or barriers in the context of participation.

The data were transferred into the analysis program IBM SPSS Statistics 21 (Wahlgren, 2012) in form of descriptive statistics. The non-numeric variables were presented at nominal- and ordinal scale and coded with numbers prior to the transference (Kristensson, 2014). The numbers used for coding the different answers were the same as those presented in the

instrument (UNICEF in prep, see appendix 1), in order to make the transference of data as easy as possible. Each of the 19 activities were coded with the same number as the ones presented in the instrument (UNICEF in prep, see appendix 1). The answers in the category “Frequency of involvement” were coded with numbers. “Always” with number “6”, “Sometimes” with number “5”, “Not really” with number “4”, “Never” with number “3”, “N/A” with number “2” and “Unsure or no answer” with number “1”. The answers in the category “Level of involvement” were also coded. “Very” with number “5”, “Somewhat” with number “4”, “Not” with number “3”, “N/A” with number “2” and “Unsure or no answer” with number “1”. Finally the answers in the category “Barriers and Facilitators” were coded. “Facilitator (easier)” with number “5”, “Barrier (harder)” with number “4”, “Neutral” with number “3” and “N/A” with number “2”.

The data analysis of the final step, “Barriers and Facilitators” differed from the prior steps. As shown in Table 5, the children had to identify barriers and facilitators in relation to the three prioritized activities, and there were seven different areas in the category of “Barriers and Facilitators”, which resulted in a total of 21 different answers per child (see appendix 6). Given that this would be a too high number of variables and answers to present, the authors chose to only present a general picture of the children’s perception of what enabled or restricted participation in activities in daily life. While typing in the data collected in the category “Barriers and facilitators”, mode was used. If a child for example answered 4 (Barrier), 5 (Facilitator) and 4 (Barrier) under “Services and policies”, the authors chose number four (Barrier), since it was the most frequent number. If the child answered 5 (Facilitator), 4 (Barrier) and 5 (Facilitator), the authors chose number five (Facilitator). If the child instead had answered 3 (Neutral), 4 (Barrier) and 5 (Facilitator), the authors chose to interpret it as a “Non-response” since no mode could be deduced.

Table 5. Scoring sheet for barriers and facilitators

<b>Most important activities</b>	<b>Barriers and Facilitators</b> <b>B=barrier</b> <b>F=facilitator</b>						
	Services and policies	Physical environment	Social environment	Family attitudes	Community attitudes	Beliefs/value systems in the society	Personal factors
a.							
b.							
c.							

Finally, the data in IBM SPSS Statistics 21 was exported to Microsoft Excel 2013 which then was used to create the tables and diagrams needed for the presentation of the result.

## Ethical considerations

On the center in Addis Abeba, Ethiopia, the coordinators gave their approval for the authors to conduct a Minor Field Study (see appendix 7). An ethical self-evaluation of this thesis was performed prior to the data collection begun according to the guidelines of the School of Health and Welfare, Jönköping University (see appendix 8).

According to Flewitt (2005) it is important to apply ethical consideration while conducting studies with members of the society that are particularly vulnerable, in this case children with an intellectual disability. According to Hyder, Rattani, Krubiner, Bachani and Tran (2014) there are several ethical matters that should be taken into consideration while conducting a study in LMICs. It is important to show respect for the community, its members and their values while doing a study in a LMIC. It is also important that the center can benefit from the services provided during the study, also after that the study is conducted (Hyder et al., 2014). The result of the thesis was shared with the staff at the center, in order to enable them to use the knowledge.

A common ethical problem while conducting a study in LMICs is to get consent from the participants (Hyder et al., 2014). In this thesis assent was given by the children who participated in the interviews and consent was given by the parents of the children, since the children were under the age of 18. Before any interviews were carried out a letter and a consent form was given to the participants containing information regarding their rights. According to Flewitt (2005) it is important to protect the participant's confidentiality meaning there is no possibility to track the findings to the participants. The participants were also informed that they had the right to decline participation and that if they choose not to participate there would be no negative outcomes and the services provided by the center would not be affected in any way.

In this thesis an interpreter was used to interview the participants because of the language barrier. The interpreter had to sign a consent form on the subject of confidentiality. The consent form contained information about the importance of secrecy regarding the participants and that no information were allowed to be spread (see appendix 9). Since English was not the authors' nor the interpreter's native language, the trustworthiness of the thesis could be questioned because of errors or misunderstanding in the translation.

While conducting this bachelor thesis the authors were well aware of the cultural differences that existed. Because of these differences the authors took the cultural aspect in consideration at all times. Muñoz (2007) describes that to be able to gain cultural awareness and cultural knowledge it is important to reflect about yourself and the people around you as cultural beings and that everyone is different from the other. By searching for knowledge in different cultures it creates a greater understanding about how different cultures and individuals view the world. Furthermore, the author explains the term of applying cultural skills, which is defined as strategies that are used in the context of occupational therapy assessments and interventions. It includes the skills of being able to get a personal connection with patients with different cultural references. This is accomplished by being open, understanding and respectful in regard to the differences in culture. By interacting with culturally diverse individuals in different contexts it allows a person to expand his or her cultural awareness, cultural knowledge and cultural skills (Muñoz, 2007).

The Code of Ethics for Occupational Therapists, The World Federation of Occupational Therapists [WFOT] (2005) states that occupational therapists have to respect the person they are providing services for, this naturally includes the person's perspectives, values, cultural diversity and lifestyle. Furthermore, WFOT (2010a) states that “Occupational therapy acknowledges that every person is unique in the way they combine the dynamic interplay between cultural, social, psychological, biological, financial, political and spiritual elements in their personal occupational performance and participation in society”.

## Results

With the result from the interviews it was possible to answer the questions described under the heading “Aim”. These questions concern the children’s frequency of involvement, which activities they prioritized as the most important, how involved they were in the prioritized activities and if there were any facilitators or barriers in the context of participation.

### Which activities did the children participate in most frequently?

Shown in Figure 1 are the activities that the highest amount of children reported that they participated in most frequently. The majority of the children reported that they “Always” participated in “Daily routines at home for personal care (dressing, choosing clothing, hair care, brushing teeth)”. Other categories that the highest amount of children reported that they “Always” participated in were “Religious and spiritual gatherings and activities”, “Formal learning at school”, “Getting together with other children in the community”, “Family mealtime (with usual family members)” and “Paid and unpaid employment” (see Figure 1).

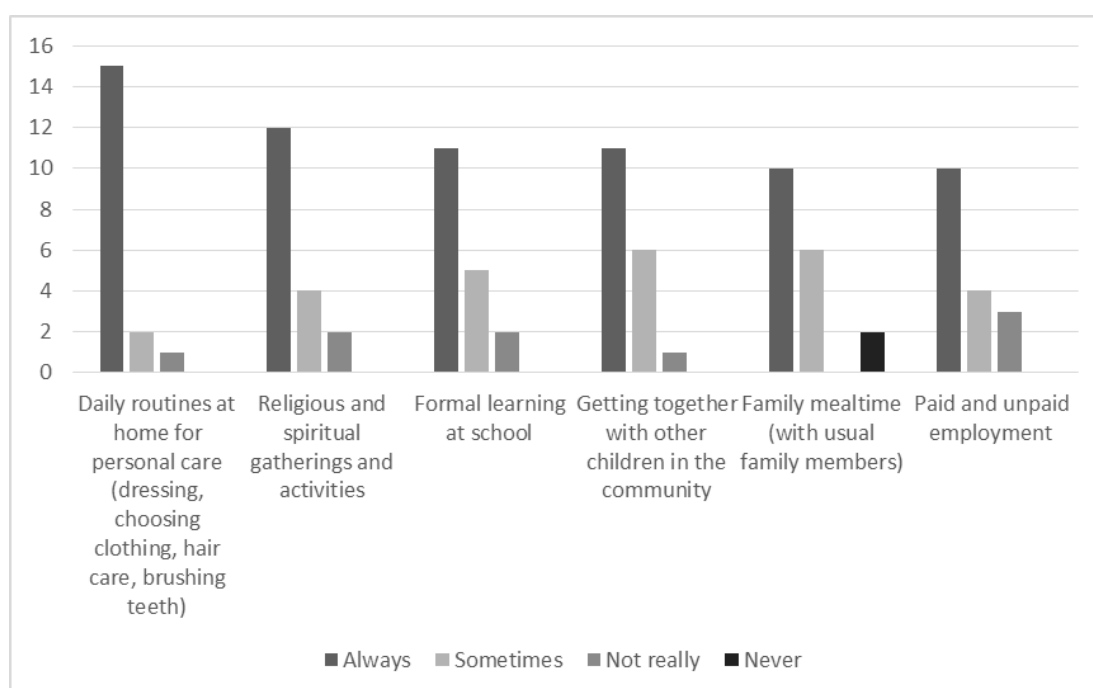


Figure 1. An overview of the activities the children participated in most frequently (n=18).

Within the activities presented as the ones the children participated most frequently in, there were also children that answered that they did not participate as frequently as the majority of the children. However “Family mealtime (with usual family members)” was the only activity within the category “Frequency of involvement” that some of the children reported that they “Never” participated in (see Figure 1.). There was one non-response within the category of “Paid and unpaid employment”.

### Which activities did the children prioritize as most important?

The activities that the children combined prioritized as the most important ones are presented in Figure 2. The highest amount of children answered that “Organised leisure activities” was the most important activity. The other activities that most of the children prioritized as the most important ones were “Meal preparation with or for the family”, “Taking part in social



activities in the community”, “Paid and unpaid employment” and “Religious and spiritual gatherings and activities” (see Figure 2).

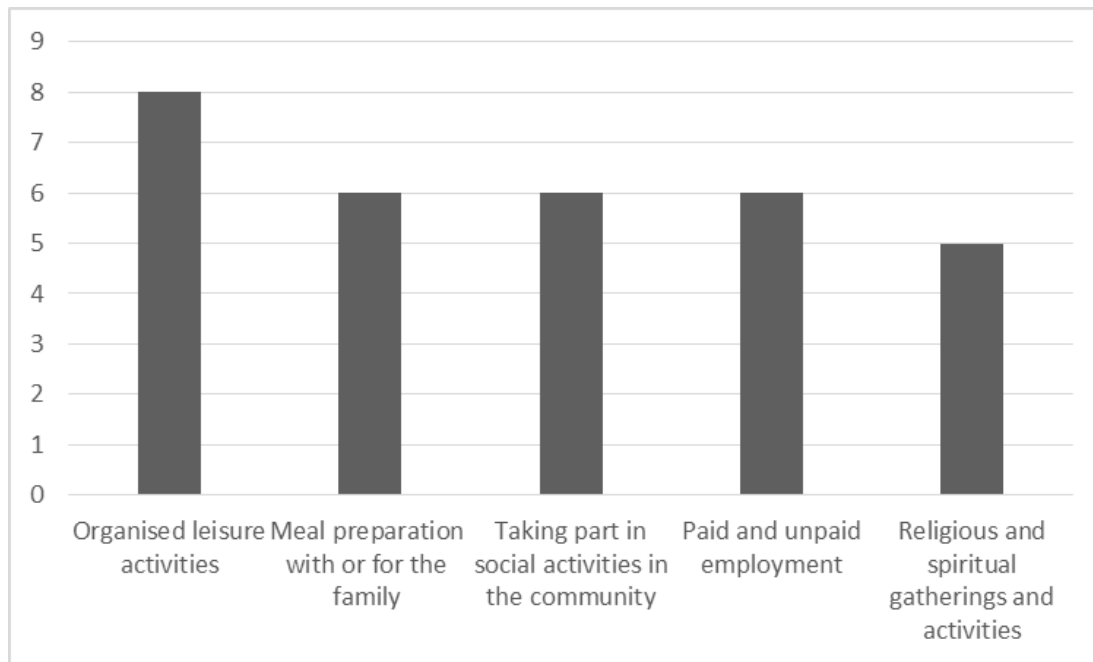


Figure 2. An overview of the activities the children combined prioritized as the most important ones (n=18).

### How involved were the children in the prioritized activities?

Shown in Figure 3 are the children’s perceived level of involvement in the most frequently prioritized activities, also shown in Figure 2. The highest number of children answered that they were “Very” involved in the most frequently prioritized activity “Organised leisure activities”. Only one child answered that they were “Very” involved in “Taking part in social activities in the community”. In the activity “Paid and unpaid employment” there was a significant deviation between the children’s perceived level of involvement. Within the category “Taking part in social activities in the community” there was one non-response.

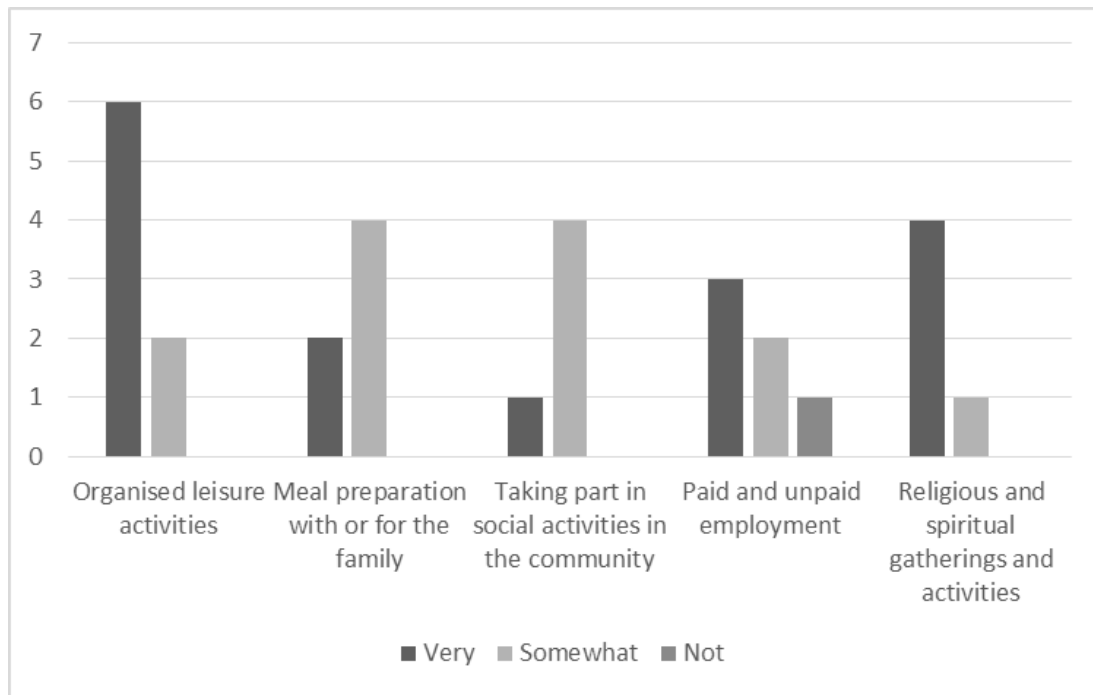


Figure 3. An overview of the children's perceived level of involvement in the prioritized activities (n=18).

Which were the facilitators or barriers affecting the children's participation in activities?

Figure 4 shows the children's perception regarding barriers and facilitators in the context of participation. The highest number of children answered that the categories "Services and policies" and "Social environment" were a "Facilitator" to participation. The highest number of children answered that "Family attitudes" were a "Barrier" to participation. The children most often saw all the categories presented as facilitators to participation in activities.

A high number of children answered "Neutral" when asked if "Beliefs/value systems in the society" were a "Facilitator" or a "Barrier" to participation. There were two non-responses in the category of "Beliefs/value systems in the society" and one non-response in the category of "Services and policies".

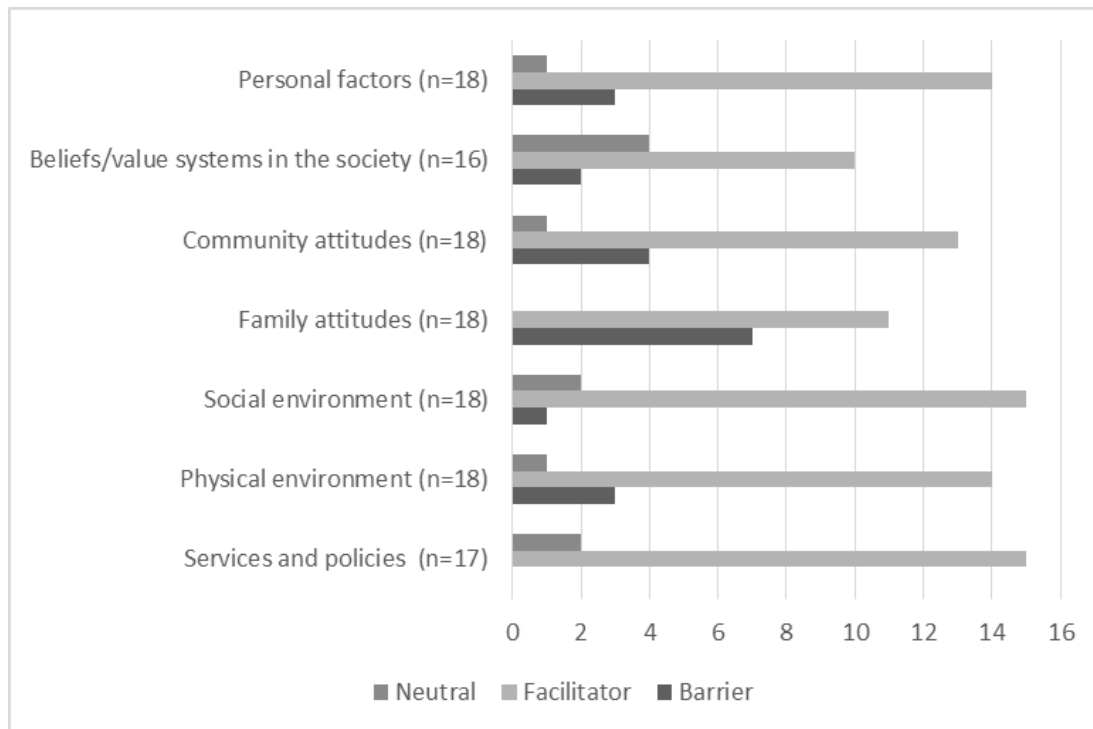


Figure 4. An overview of barriers and facilitators in the context of participation (n=18).

## **Discussion**

### **Method discussion**

#### ***Study design***

The descriptive study design was suitable because it corresponded with the aim, which was to simply present the data but make no inferences (Kristensson, 2014).

The authors believe that it would have been valuable to perform a qualitative interview study to find out the reasons behind the children's answers, for example in what way the family attitudes affected the participation. By conducting a less structured interview with open questions it could have been possible to get a more extended view on the child's own perspective on participation.

#### ***Participants***

The method of selection that was used was consecutive sampling. This method was suitable because it is a good method of selection since the authors are allowed to ask individuals to participate both before and during the data collection which contributes to a representative sample (Kristensson, 2014). Although this method of selection is supposed to give a representative sample, the question if the sample was representative for the whole population "children with intellectual disabilities in LMICs" could be asked. A speculation from the authors is that the children at this particular center were very privileged, and therefore had fewer problems in the context of participation compared to other children within the same population that did not attend this center. These facts could question the external validity of this thesis.

In total this thesis had two external drop-outs. The reason for one of the drop-outs was that the parent/s had not given their consent and the other drop out was due to that the child was not able to participate in the interview since he or she was non-verbal. According to Kristensson (2014) drop-outs can lead to questioning of the internal validity, hence this could be the case. The authors speculate that it may have been beneficial to have an information meeting with all of the parents and the children about the thesis, where they could have signed the consent form immediately after the information was given. This would maybe have given more participants. Kristensson (2014) describes that a higher number of participants enables the authors to generalize the result to other contexts than the one that the study is taking place in. This also increases the external validity of the study. Based on this fact the authors believe that it would have been valuable to have a higher number of participants, and participants from different parts of Ethiopia, in order to be able to generalize the result to other context than this specific center.

#### ***Data collection; the instrument***

Many of the children had problems with grading both within the category "Frequency of involvement" and "Level of involvement". Many children also had problems with knowing the difference of the amount of apples presented at each level at the "Frequency of involvement table". According to the translator the children often answered one thing, but then pointed at

another level on the tables. The authors took the decision to record the answer that the child had given the translator, and not what he or she had pointed at. This could of course question the validity and reliability of the instrument and this thesis.

The authors speculate about the fact that the participants had different kinds of intellectual disabilities and that it affected the results of this thesis. The interviews varied much in time, the shortest one was 25 minutes and the longest one was 65 minutes. The authors speculate that the time spent in each interview depended on how much the child understood and how well they could express themselves. Those interviews that took the longest time were also performed with children who had problems with concentration. Therefore, this instrument may not be the most appropriate one for children with concentration difficulties or intellectual disabilities.

According to Pendzick and Demi (2009) it is common that people with intellectual disabilities have problems with abstract thinking. Based on this fact the authors believe that some of the pictures in the instrument were hard for the children to understand. The picture representing "Organised leisure activities" seemed to be somewhat confusing for the children since the child in the picture is playing three different sports at the same time. This activity is also supposed to contain clubs, music, art and dance, but the children seemed to only focus on the soccer. The picture for "Taking part in social activities in the community" also seemed to be a bit hard for the children to understand. On the picture there are three children playing in a band, but the intention is in fact to ask the child if he or she participates in social activities in the society, such as playgroups, parties and parades. This was problematic for the children to understand. The picture representing "Paid and unpaid employment" was also difficult for the children to understand. On the picture it looks like the child works in the garden, but the fact is that in this culture is also common to work at the minibuses, selling things on the street and so on. Overall it seemed like the majority of the children had some trouble with generalizing what they saw in the pictures to other activities or situations.

Many of the pictures in the section of "Barriers and facilitators" in the instrument seemed to be difficult for the children to understand. The picture representing "Services and policies" had a number of flags from different countries. These flags were confusing for the children. They started to explain which flag that belonged to which country and lost their concentration on the task. Additionally the translator explained that the children did not understand this concept at all. The authors believe that all concepts under "Barriers and facilitators" should be simplified as well as the pictures representing them.

The picture for "Social environment" was a child sitting in a wheelchair and a friend pushing the child. This category included support/relationships and products and technology. This was confusing for the children since they thought that this was the same as the attitudes of the family and the community, which are two categories that comes later in the instrument. The authors believe that telling the child that the same category can mean two different things, brings confusion to the child.

On the picture for "Beliefs/value systems of society" there are nine different symbols for different religions. This made it hard for the children since it was not adapted to their culture and religion. The children often started to explain the meaning of the different symbols and lost focus on the question that was asked.

The authors think that some picture should be added to the instrument, for example “Visit others”, which is very common in this culture. Another thing that the authors felt missing was a picture representing “Taking care of animals/livestock”, which according to Haile and Haile (2012) also is something that is very common for children to do in this culture. The authors also speculate that it seemed like many of the pictures were just a distraction for the children during the interview. In some cases the authors felt like it would have been easier to just ask the children the questions without using the pictures.

The authors of this thesis think that it should be clarified in the instrument exactly what the test leader should ask and how much you are allowed to explain to the child if he or she does not understand the question. As the instrument is designed now, there is too much room for interpretation. This could lead to a decreased validity and reliability since different persons may ask questions in different ways.

Step number 2a and 2b in the instrument should change place. The authors think that it would be easier for the child to understand if the test-leader first explains that he or she will show some pictures for the child, and then explain the frequency of involvement table.

### ***Data collection; procedure***

The translator had experience in interpreting since earlier but had not worked with children with intellectual disabilities before. The authors think that this might have influenced the children’s answers. Since he did not have any experience nor knowledge in regard to communicating with children with an intellectual disability the validity and the reliability might be questioned. By having a translator with more experience in the field of working with children with an intellectual disability it could have been possible to improve the children’s understanding.

The interviews were performed in two different rooms, which may have affected the result. Furthermore, the environment may not have been optimal to conduct interviews since there were a lot of windows facing the playground and there were no possibility to cover them. It is possible that this might have influenced the children’s concentration and thus the answers that were given. Another thing in the environment that could have affected their answers was the fact that the rooms were not soundproof. All these factors may have affected the internal validity of this thesis in a negative way.

The interviews might have been conducted somewhat differently from one session to another. When there are two persons that are conducting the interviews there is a higher risk that the questions will not be asked in the same way at each separate interview. At the same time it was beneficial that both of the authors were present during the interviews, since one conducted the interview and the other recorded the numbers that corresponded with the child’s answers on the score sheets. The person conducting the interview could thereby concentrate on the child and both authors could control that the numbers written down on the scoring sheet were the correct ones. This may have increased the internal validity of this bachelor thesis.

## ***Data analysis***

The authors found IBM SPSS Statistics 21 to be complicated when working with the data analysis, which might be because of the lack of knowledge about the program. Therefore, the authors chose to make the tables and diagrams in Microsoft Excel 2013 instead of IBM SPSS Statistics 21 since this program was easier to manage. When analyzing the data the authors got supervision from one of the authors of the instrument because of a lack of information about how to compile the collected data. Since the data analysis was performed by both authors, the accuracy of the result was increased.

## **Result discussion**

### ***Frequency of involvement***

“Daily routines at home for personal care (dressing, choosing clothing, hair care, brushing teeth)” was the activity that most children reported that they “Always” participated in. The authors speculate that the reason behind this could be that the cultural values in this community is that it is important to take care of your hygiene. Another reason could be that this is something that the children learn in school. Every morning the children have to clean themselves before class starts and in the beginning of the class they also have to tell their classmates about their morning routines. According to Kielhofner (2008) habituation can be seen as a guide for people’s behavior and the way that people do it is by having habits and roles. Thus, habits are something that is created by doing certain activities in the same kind of context. These habits make it possible to respond and perform activities in an accustomed context or environment. A lot of the things that people do in their daily life is therefore guided by the habits that people have. Roles are something that can be seen as a social identity, these make people act in the way that they are expected since it is a part of their social identity. Roles are also something that creates a person’s values, attitudes and behavior.

Another activity that a high number of children answered that they “Always” participated in was “Religious and spiritual gatherings and activities”. In this culture religion plays a major part in people’s lives. The school is also religious. In the school they start the day with prayer in the morning and they also pray before mealtime. The authors believe that it affected the results. According to the results of a study made by Shogren and Rye (2005) the participants, individuals with an intellectual disability, rated religion as something important in their daily life. This is something that is transferable to this bachelor thesis since a lot of the children were participating in this specific activity.

“Formal learning at school” was also an activity that many of the children answered that they “Always” participated in. The authors believe that the reason behind this was that the children at this school come here every weekday. These children have the opportunity to go to school, which is not common for most of the children with a disability living in LMICs. According to ACPF (2011) 73,8 percent of the children with a disability living in Ethiopia do not attend school. In fact, children with intellectual disabilities seem to be the group that has the highest risk of being excluded from school in Ethiopia. The authors believe that the children attending this center were very privileged, meaning that they are allowed to attend school, which may have influenced the children’s answers.

The activity “Getting together with other children in the community” was also one of the activities that many of the children answered that they “Always” participated in. An assumption from the authors is that the children answered like this because it is common for them to spend a lot of time playing together with their classmates during the breaks every day in school. This result also corresponds with the results from a study performed by Harding et al. (2009) where the participants answered that “social activities” was something that they often participated in.

According to Kielhofner (2008) culture is a part of the environment, which, in turn, is something that affects a person’s participation in an occupation. A high number of children answered that they “Always” participated in “Family mealtime (with usual family members)”. In this culture the concept of family is very strong and it is common to live with your parents even after the time when you have become an adult. It is also common to eat together and that several people share the food on one plate. The authors speculate that these cultural values influence the actions of the people in this country and are the reason behind that this activity was one of those that the children reported that they “Always” participated in.

Finally “Paid and unpaid employment” was an activity that many of the children answered that they “Always” participated in. Many of the children in this country have some kind of paid or unpaid employment, for example helping a family member to run a minibus, selling things on the street, working in the garden and so on. Many children also help out with chores in their home, which the authors believe that the children also associated with employment. According to Haile and Haile (2012) children from Ethiopia begin to work when they are young. It is common that they work both inside and outside of the family household.

One child answered that they “Never” participated in the activity “Family mealtime (with usual family members)”. A speculation from the authors is that the reason behind this is that children, and especially children with some kind of disability, do not have the same value as other family members. This may result in that the child is not allowed to participate during family mealtime.

### ***Prioritized activities***

“Organised leisure activities” was the activity that most children prioritized as the most important one. Soccer was one of the sports that was shown at the picture representing this activity and this is a very important part of the children’s lives and something that they do every day in school. The authors speculate that this is why so many of the children chose this activity as the most important one. “Organized leisure activities” was not an activity that the children participated in most frequently. Despite this the children prioritized this activity as one of the most important one and they scored their level of involvement in this activity as the highest.

As described under the heading “Which activities did the children participate in most frequently?” the activities “Paid and unpaid employment” and “Religious and spiritual gatherings and activities” were two of the activities that the children participated in most frequently. These activities were also two of those that the children prioritized as most important. The authors speculate that if you do an activity often, it is also common that this activity is something that you as a person value as an important activity. Kielhofner (2008)



talks about the concept of volition, our motivation to perform different activities. It can be seen as the importance or the value that a person puts in something they do. It can also be seen as the happiness or satisfaction that a person gets while doing a certain activity. It is therefore important to know that what people want to do depends on their personal values, what is satisfying and if they feel skilled in the activity. Similarly, Shields, Synnot and Kearns (2015) showed that the children chose to participate in activities that they preferred to participate in. Based on these facts the authors believe that there is a connection between which activities the children participate in often and which activities that they prioritize as most important.

“Taking part in social activities in the community” was also one activity that the children prioritized as important. It is the authors’ understanding that it is common to prioritize the needs of the group before the needs of the individual in Ethiopia. It is a big part of the culture to spend time with others and take part in different kinds of social events and activities. This result correspond with the results from a study performed by Shields et al. (2015) that show that the children most often preferred to participate in social activities.

Finally, the activity “Meal preparation with or for the family” was prioritized as one of the most important activities. In Ethiopia the people are very proud of their coffee and the ceremony that is performed while making it. The children learn how to make the coffee and perform the ceremony at school. According to ACPF (2011) it is common and expected that children living in Africa help out and contribute a lot at home, including cooking for the family. It is also common that children with disabilities are forced to perform more tasks in the household than their siblings. However, many children see this type of work as meaningful since they are contributing to their family. The authors speculate that these facts may have influenced the children’s answers.

### ***Level of involvement***

Most of the children perceived their involvement in the prioritized activities as “Very” or “Somewhat” involved, which was a more positive result than the authors had anticipated. After reading articles about how they look on the concept of disability in LMICs, for example as described by Lyngnegård et al. (2013) that it is common that the children are hidden from the rest of society by their family which leads to isolation, the authors expected to get a much higher frequency of the answer “Not”. The authors speculate that there could be a reason behind this results. There could be a correlation between the activity that the children prioritized as most important and the level of involvement. It could be that the children prioritized the activity as the most important one, because of the fact that they had a high level of involvement in that specific activity. The authors also speculate that the children were more highly involved than others because they had a lot of support from the school and they participated in the activities at school. The activity “Organized leisure activities” was the activity that the children prioritized as the most important one, and also the activity that they reported being most involved in. This result is similar to those found in a study performed by Shields et al. (2015) where the children reported that they were more likely to participate in an activity that they preferred to perform.

One child answered that it was “Not” involved in the activity “Paid and unpaid employment”. The authors speculate that the reason behind this could be that this specific child might experience that it does not have the capacity needed to perform this activity. According to

Kielhofner (2008) a person's performance capacity depends on different factors such as musculoskeletal and/or mental or cognitive abilities. The concept builds on the fact how we are able to do certain activities but also how diseases or impairments may influence our subjective experience and our capacity to perform activities. All these factors combined influence a person's participation in occupation.

The authors speculate whether socioeconomic class affected the children's perceived level of involvement. If the child lives in a family that has a high standard of living it may be more privileged than other children with similar disabilities that belongs to another socioeconomic class. Shields et al. (2015) showed that children with disabilities living in areas that were disadvantaged concerning socioeconomic status participated less in activities.

### ***Facilitators and barriers***

The majority of the children answered that they most often saw all the categories presented as facilitators to participation in activities. This result correspond with the results found by Harding et al. (2009) where the participants most often saw supports to participation rather than barriers. Furthermore, Kielhofner (2008) describes that personal factors and environmental factors can facilitate a person's participation in occupation, and the fact that a person has a disability may change his or her ability to participate, but this does not mean that it restricts a person's participation in occupation.

The result show that the children most often see the attitudes of their family as a "Barrier" to participation in activities in everyday life. The authors speculate that this could in fact be true. According to Lyngnegård et al. (2013) it is common that the beliefs of the community are that children with disabilities are embarrassing, shameful, and should not be shown to other people. This can contribute to loneliness and isolation among children with disabilities. Additionally, this result corresponds with the results from a study performed by Harding et al. (2009), which showed that the participants viewed their parents as a barrier to participation since they sometimes gave them different kinds of restrictions. Kielhofner (2008) describes that the social environment, such as the values of the family, is something that can restrict a person's participation in occupation. Furthermore, the author states that having an intellectual disability may contribute to alienation and isolation from the rest of the society.

The category "Believes/value systems in the society" seemed to be too abstract for the children to understand, which resulted in a high number answering "Neutral" when asked if this was a facilitator or a barrier in the context of participation. Lyngnegård et al. (2013) describes that the cultural beliefs held by the family and the society can contribute to isolation for children with disabilities. The authors speculate that it can be a reason why the children had hard time understanding the concept of "Believes and values" since they might be hidden from the society by their families.

Under barriers and facilitators many of the children had problems with understanding the concept of "Services and policies" and how this concept would affect them in the performance of an activity. The category "Services and policies" was the one that the children had the most problem understanding, but at the same time this was the category that the most children selected as a "Facilitator" to participation. The translator explained that this concept also is hard for adults living in Ethiopia to understand, since there is a lack of services and policies

within the country. The authors also speculate that many people living in Ethiopia have respect for and are afraid of questioning the government and that this could have affected the answers from the children. Kielhofner (2008) describes that economic and political environments affect a person's performance of activities, especially people with disabilities. This may result in preventing people with disabilities from getting access to rehabilitation services, getting an employment, achieving independence and having lives with positive occupations.

## The importance for occupational therapy

The result of this bachelor thesis may contribute to a better understanding about children with intellectual disabilities living in LMICs. This thesis may have contributed to more knowledge about the children's own perspective and about what factors they see as barriers in the concept of participation. This knowledge is extremely important for occupational therapists, in order to be able to address the problem and plan suitable interventions. As also described in the results of a study performed by Shields et al. (2015) the result of this bachelor thesis may contribute to knowledge about the importance of taking the children's preferences into consideration while planning interventions to facilitate participation in activities. Additionally, the results of this thesis could lead to the development of new work methods about how to approach this group to enable participation in activities in everyday life. These work methods could be applied while working with refugees coming to Sweden, but also while working with children living in LMICs.

With this knowledge the authors can emphasize the need of occupational therapy in developing countries and hopefully contribute to the development of an occupational therapy program which will lead to more active occupational therapists in Ethiopia. By acknowledging the importance of participation in activities in everyday life occupational therapists strengthen the need of the profession as well as the theories that lies as a foundation for the profession. WFOT (2010b) clearly states that occupational therapy focuses on giving individuals the aid to be able to change their view on their own person, the occupation, the environment or a mixture of them all to increase participation.

By testing and evaluating the usefulness of "Picture my Participation" the authors of this thesis have contributed to the development of the instrument. This could be valuable since this instrument might be used in future assessments performed by occupational therapists involving children living in LMICs.

## Future research

There is a need of future research in order to develop this instrument further. Questions have to be asked about which children the instrument is suitable for and if the instrument is applicable in developing countries. The authors also wish that the opportunity to adapt the instrument to the cultural context that the interview is taking place in is given, as well as the opportunity to adapt it to the child in front of you. Furthermore, the authors believe that it could have been valuable to investigate the correlation between different variables, for example if a factor that the child view as a barrier affects the level of involvement in a specific activity. Kristensson (2014) describes that an instrument should have a low level of error of measurement. To reach this there are different ways to test the reliability including test-retest, interrater reliability and intrarater reliability. The authors believe that "Picture my

Participation” is in need of future development in forms of tests of the reliability and the validity of the instrument.

The authors of this bachelor thesis believe that future research about children and their own perspective is needed. Furthermore Lygnegård et al. (2013), Harding et al. (2009) and Hammarlund (2015) all emphasizes research regarding children and their own perspective since this kind of knowledge is limited and needs to be developed further.

## Conclusion

In conclusion the children perceived their participation in the prioritized activities as high and experienced few barriers in the context of participation. The activity that the highest number of children reported that they participated most frequently in were “Daily routines at home for personal care (dressing, choosing clothing, hair care, brushing teeth)”. The activity that highest number of children prioritized as most important was “Organised leisure activities”, which also was the activity that most children reported being most involved in. Other activities that the children combined prioritized as most important were “Meal preparation with or for the family”, “Taking part in social activities in the community”, “Paid and unpaid employment” and “Religious and spiritual gatherings and activities”. The children combined most often saw “Facilitators” in the context of participation, where “Services and policies” and “Social environment” were the factors most often seen as “Facilitators”. However, “Family attitudes” was the factor that the highest number of children viewed as a “Barrier” to participation.

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### PICTURE MY PARTICIPATION (INTERVIEW SCHEDULE)

#### Administration of the Interview schedule

##### *Test population*

Picture my Participation has been developed for children aged 5 to 17 who have a disability. Disability is an umbrella term, referring to impairments (a problem in body function or structure), activity limitations (a difficulty encountered by an individual in executing a task or action), and participation restrictions (a problem experienced by an individual in involvement in life situations). It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives (WHO, 2015). The tool will need to be adapted for children with a sensory loss (vision, hearing) or a parent proxy could be used. If a parent proxy is used this needs to be identified on the test information form.

##### *Test environment*

Picture my Participation should be administered in an environment where the child is comfortable.

##### *Equipment required*

- Talking mat
- Participation cards
- Score sheet
- Pen or pencil for recording

##### *Administration time*

The assessment takes approximately 20 minutes to administer depending upon the child's ability to follow instructions. Prior to administration the assessment, the setting up of the test equipment takes approximately 2 minutes and packing up requires about 2 minutes. The scoring takes approximately 5 minutes.

##### *Qualification of test administrators*

Test administrators can be from any background. The tool has been designed so that 'expert training' is not required for its use, but rather an eLearning tutorial. This tutorial will provide an understanding of the ICF, the rights of a child, and the construct of participation, concepts central to 'Picture My Participation'.

It is essential that the test users complete the tutorial, read the manual completely and are familiar with the requirements of each sub-section of the assessment prior to administration. *Test items and instructions*

### Step 1: Introduction to child and assent procedure

“We want to hear your story about who you are and what you do. Your story is important to us because we want to understand about your involvement with your home, school and community. We are interested in how often you do activities, how involved you are in the activities and what things make it easier and more difficult to participate. There are no right or wrong answers just sharing of ideas. We understand that this is your story and that we will not talk to other people about it.

### Step 2: Frequency

a. Place the frequency template in front of the child and explain the levels of frequency using clear plain and appropriate language.

#### Frequency table

<b>Always</b>  <b>(6)</b>	<b>Sometimes</b>  <b>(5)</b>	<b>Not really</b>  <b>(4)</b>	<b>Never</b>  <b>(3)</b>	<b>N/A</b> <b>(2)</b>	<b>Unsure or no answer</b> <b>(1)</b>

#### Frequency of involvement

Score	Level	Definition
6	Always	The child participates all of the time
5	Sometimes	The child participates some of the time
4	Not really	The child occasionally/rarely participates
3	Never	The child does not participate
2	N/A	Not relevant to the child
1	No or ans wer unsure	The child does not know the answer or does not answer at all

## Appendix 2

### **Participation in activities in everyday life**

Participation is defined as the involvement in a life situation and participation in everyday activities is an important part of life and the human development. Children with disabilities as a group are particularly vulnerable to experience participation restrictions due to problems in the interaction between the child and its social and physical environment.

Very few studies have been made that focus on children living in low and middle income countries, their own perspective and how they perceive their life situation, therefore this kind of research is needed.

#### ***What is the aim of this project?***

The aim of this project is to describe how children aged 13-17 with an intellectual disability perceive their situation regarding participation in activities in everyday life.

#### ***Who will participate?***

Children between the ages of 13-17 who attends the center will be asked to participate in an interview. The goal is to have about ten participants.

The participation is voluntary, the children have a right to decline participation at any time and if they choose not to participate there will be no negative outcomes. The answers will only be used in this project, and possibly in future research. To participate we need the consent of both the legal guardian(s)/parent(s) and the child.

#### ***How will this project be conducted?***

At first children and parents will receive written information about the project. If the child wants to participate we will interview him/her and ask questions about how often the child participates in activities, how involved the child is in the activities and if there is anything that stops the child from doing activities. The child is asked to answer by using pictures that will be shown during the interview. The interviews will be conducted at the center with one participant at a time and will take about 30 minutes. A translator will attend the interview to translate between Amharic and English. Under special circumstances a parent or a teacher may attend the interview.

#### ***Confidentiality***

The collected answers will be kept safe on an encrypted hard drive and no unauthorized persons will get access to the information. The result of this project will be compiled so that no outsider can recognize the center, the children participating or their family.

The translator will have to sign a document regarding confidentiality containing information about the importance of secrecy regarding the participants and that no information is allowed to be spread.

### ***Information about the result***

The final results of this project will be presented in our bachelor thesis which will be sent to the center in form of a printed copy.

### ***Benefits***

By conducting this project we hope to enable the children to tell their own story about participation in activities in everyday life. By understanding what factors that facilitates or inhibits the children's participation, suitable interventions can be developed and implemented in the future.

### ***Responsible***

Hampus and Sara. If you have any questions you can talk to us at the center or send an e-mail.



Hampus Palmberg  
E-mail: [hampus.palmberg@outlook.com](mailto:hampus.palmberg@outlook.com)



Sara Abrahamsson  
E-mail: [saraaa\\_93@live.com](mailto:saraaa_93@live.com)

### ***Supervisor***

Elisabeth Elgmark  
Phone: +46702479276  
E-mail: [elisabeth.elgmark@ju.se](mailto:elisabeth.elgmark@ju.se)

## Appendix 3

### Can you tell us what you do during the day?



#### ***What do we want?***

We would like you to tell us what you do during the day.

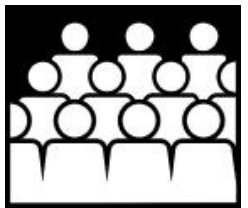


#### ***Why do we want it?***

We want to understand what **you** think.

#### ***Who will participate?***

10 children between the ages of 13-17 who attend this center.



#### ***Does everyone have to participate?***

No, you do not have to participate if you do not want to. You can end your participation at any time without anything bad happening.

#### ***Who will attend the interview?***

Hampus and Sara, a translator and you. If you want you can bring a parent or a teacher.



#### ***What will happen during the interview?***

We will ask you questions about what activities you do, how often you do them, how involved you are and if there are things that stops you from doing activities. You can answer by using pictures.



#### ***What will happen with your answers?***

Your answers will be kept in a safe place. The answers will only be used in this project and maybe in future research. Only Sara, Hampus and the translator will know what you have answered.



***Why is this project good?***

Because you get to tell us what **you** think.

***Who are we?***

Hampus and Sara. If you have any questions you can talk to us at the center or send an e-mail.



Hampus Palmberg

E-mail: [hampus.palmberg@outlook.com](mailto:hampus.palmberg@outlook.com)



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## Appendix 4

### **What activities does your child do during the day?**

#### ***What do we want to do?***

We would like to talk to your child about what activities he/she are doing during the day and if there are anything that stops him/her from doing these activities.

#### ***Why do we want to do it?***

We would like to know what **your child** thinks.

#### ***Who will participate?***

All children between the ages of 13-17 who attends the center will be asked to participate in an interview. The goal is to have about ten participants.

The participation is voluntary, the child have the right to end their participation at any time without anything bad happening and the services provided by the center will not be affected in any way. To participate we need a consent from both you and your child.

#### ***What will happen during the interview?***

If your child wants to participate we will ask questions about what activities the child does, how involved the child is in the activities and if there is anything that stops the child from doing activities. The child is asked to answer by using pictures.

The interview will take place at the center and a translator will attend the interview to translate between Amharic and English. The translator will have to sign a document of secrecy containing information that no answers is allowed to be spread.

Under special circumstances a parent or a teacher may attend the interview.

#### ***What will happen with the answers?***

The answers will be collected and kept safe and will not be able to be tracked back to the child, the family or the center. The answers will only be used in this project and possibly in future research.

#### ***Why is this project good?***

Most of the previous research has focused on the thoughts of parents and caregivers, therefor it would be valuable to also learn about the child's perspective.

#### ***Where can you find the result?***

The final report will be sent to the center in form of a printed copy. You can get access to it by contacting the coordinator at the center.

***Responsible***

Hampus and Sara. If you have any questions you can talk to us at the center or send an e-mail.



Hampus Palmberg

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***Supervisor***

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## Appendix 5

### Consent form

We have read and/or listened to the information about the project: "*Children with an intellectual disability and their perceived situation regarding participation in activities in everyday life*".

We understand that it is voluntary to participate and that we can end the participation at any time without explaining why and without anything bad happening.

We understand that the answers only will be used in this project and possibly in future research.

We have been given the opportunity to ask questions about the project and have gotten the answers we need.

### The caregiver

Yes, \_\_\_\_\_ is allowed to participate in this project

\_\_\_\_\_

Date

\_\_\_\_\_

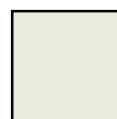
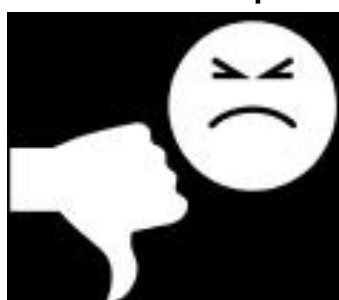
Signature Caregiver

### The child

Yes, I want to participate



No, I do not want to participate



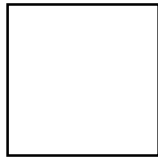
\_\_\_\_\_

Signature Child

## Consent form

The caregiver(s) of \_\_\_\_\_ have read and/or listened to the information about the project: "*Children with an intellectual disability and their perceived situation regarding participation in activities in everyday life*".

**My/our child is NOT allowed to participate in this project**



---

Date

---

Signature Caregiver

## Appendix 6

### Appendix 3: Recording sheet Part A

participation	Frequency
1. Daily routines at home for personal care (dressing, choosing clothing, brushing hair or teeth)	
2. Family mealtime (with usual family members)	
3. Looking after his/her own health (medication)*	
4. Gathering daily necessities for the family (water, food, picking vegetables, fuel)	
5. Meal preparation with or for the family	
6. Cleaning up at home (clothing, house-hold objects, laundry, rubbish, yard work)	
7. Taking care of other family members	
9. Interact with the family	.
10. Family / community celebrations (birthdays, weddings, holiday gatherings)	.
11. Getting together with other children in the community	.
12. Organised leisure activities (sports, clubs, music, art, dance)	.
13. Quiet leisure (listening to music, reading)	.
14. Religious and spiritual gatherings and activities	.
15. Shopping and errands (market)	.
16. Taking part in social activities in the community (parties, play group, parades)	.
17. Visit to health center (e.g. Doctor, dentist, other health care service)	.
18. Formal learning at school	.
19. Overnight visits and trips	.
20. Paid and unpaid employment	
Other (a)	.
Other (b)	.
Total	.

### Appendix 3: Recording sheet Part B

Most important activities	Involvement	Barriers and Facilitators B=barrier F=facilitator						
		Services and policies	Physical	Social	Attitudes (family)	Attitudes (community)	Attitudes (beliefs/values)	Who you are
a.								
b.								
c.								



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THE ETHIOPIAN EVANGELICAL CHURCH MEKANE YESUS  
DEVELOPMENT AND SOCIAL SERVICES COMMISSION

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SERVING THE WHOLE PERSON

September 10, 2015

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Ref. No. CMCC/070/2015  
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Date \_\_\_\_\_

### To Whom It May Concern

Please allow this to serve as an invitation letter confirming that the following occupational therapist students are welcome to do their Minor Field Studies (MFS) at the EECMY development and Social Service Commission -Center for Mentally Challenged Children (DASSC-CMCC), Addis Ababa, Ethiopia at Houndé, in spring 2016:

Sarah Berger  
Sandra Andersson  
Sara Abrahamsson  
HampusPalmberg

Mrs. Adanech Mekonnen will serve as the contact person at the site who can support and advise the students with practical arrangements related to their occupational therapy studies before and during the fieldwork. Please feel free to contact me if you have any further questions.

With regards!!

  
Adanech Mekonnen

CMCC Coordinator

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website: [www.eecmydassc.org.et](http://www.eecmydassc.org.et)

**Commercial Bank of Ethiopia – EECMY-DASSC – Account Number 01718/335206/00 (3170)**

«መልካም ማድረግን ለሌሎችም ማክፈልን አትርሱ፤ እንዲህ ያለው መስማዎት እግዚአብሔርን ደስ ያስኾዋልና።» ዕብራውያን 13:16  
"DO NOT FORGET TO DO GOOD AND TO SHARE WITH OTHERS, FOR WITH SUCH SACRIFICES GOD IS PLEASED" HEB. 13:16

## Appendix 8



JÖNKÖPING UNIVERSITY  
School of Health and Welfare

### Ethical Considerations for Student's Thesis

**Project title:** Children with an intellectual disability and their perceived situation regarding participation in activities in everyday life

**Student/students:** Hampus Palmberg and Sara Abrahamsson

**Supervisor:** Elisabeth Elgmark


1.	Can the project involve any risks for the participant? (patient, subject, informant)?	Yes	Possibly	No
a/	Medical risk	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
b/	Pain	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
c/	Threat to personal integrity	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
d/	Other discomfort	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
2.	Can it be guaranteed that the participants will not be identified in the results of the project?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	Are the participants involved in the project on their own free will?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	Can the participant, at any time and without reason, withdraw their participation?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.	Will the study include a register of participants, if yes who is responsible for the register and to whom is the register reported?	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
	..... (person responsible for registration)			
6.	How is the written information presented?			
a/	Is the project described in a way that the participants understand the purpose of the study. (no technical terms, plain English)	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b/	Is it clear that the patient's treatment/care will not be influenced by the choice to participate in the study or not?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c/	Is it clear that the patient's treatment will not be influenced by the choice to withdraw from the study?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.	Will the results be shared with the participants?	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The questions above are answered correctly.

Jönköping, date:  
20160222

.....

  
Student/students

  
Supervisor

## Secrecy form for the translator

I hereby promise not to spread nor use any information that I take part of during the interviews. I have received and understood the information given to me about confidentiality. I will protect the personal information of the participants, including but not limited to name, identity, diagnosis, age, ethnicity, social class and religion.

Date and place: \_\_\_\_\_

Signature: \_\_\_\_\_

Name: \_\_\_\_\_

Contact information to the students conducting this study:

Sara Abrahamsson, 0966-716009

Hampus Palmberg, 0966-716010

Supervisor: Elisabeth Elgmark, [Elisabeth.Elgmark@ju.se](mailto:Elisabeth.Elgmark@ju.se)