



JÖNKÖPING UNIVERSITY

*School of Health and Welfare*

# Children with intellectual disabilities' perceptions of their participation in activities in everyday life – a pilot study

A minor field study conducted in Ethiopia

**MAIN SUBJECT:** *Occupational Therapy*

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## **Abstract**

**Background:** Children with disabilities living in low and middle income countries' perceptions of participation are not shown in research. These perceptions are important for providing appropriate interventions.

**Aim:** To describe how children aged 8-12 with an intellectual disability living in Ethiopia perceive their situation regarding participation in activities in everyday life.

**Method:** A descriptive design with a quantitative approach was used. The sample was gathered using consecutive sampling. Fifteen structured interviews were conducted, using "Picture my participation," an instrument under development. Analyses were made using SPSS Statistics and Microsoft Excel.

**Results:** The children perceived that they participated in activities in everyday life. There was a broad variation in the activities the children prioritized as most important. On a group level, they were very involved in these activities. The majority did not experience any barriers to perform these activities.

**Conclusions:** The perceptions of the majority of the children were that they were involved in daily activities. They did not experience any barriers to participation. The results should be read with caution and generalization is not possible, due to the sample characteristics and that the instrument is under development.

**Keywords:** Low and Middle Income Country, Occupational Therapy, Picture my participation, Sub-Saharan Africa

## Sammanfattning

**Barn med intellektuella funktionsnedsättningars uppfattning av sin delaktighet i vardagliga aktiviteter – en pilotstudie. En mindre fältstudie genomförd i Etiopien.**

**Bakgrund:** Barn med funktionsnedsättningar som bor i låg- och medelinkomstländernas uppfattningar om delaktighet är inte påvisade i forskning. Dessa uppfattningar är viktiga för att tillhandahålla lämpliga interventioner.

**Syfte:** Att beskriva hur barn i åldrarna 8-12 år med en intellektuell funktionsnedsättning som bor i Etiopien uppfattar sin situation gällande delaktighet i vardagliga aktiviteter.

**Metod:** En deskriptiv design med kvantitativ ansats har använts. Urvalet har samlats in genom konsekutivt urval. Femton strukturerade intervjuer genomfördes med användning av "Picture my participation", ett datainsamlingsinstrument under utveckling. Dataanalysen gjordes i SPSS Statistics och Microsoft Excel.

**Resultat:** Barnen uppfattade att de deltog i vardagliga aktiviteter. Det var en stor variation i vilka aktiviteter barnen prioriterade som viktigast och på gruppnivå var de mycket delaktiga i dessa aktiviteter. Majoriteten av barnen uppgav att de inte upplevde några hinder för att utföra dessa aktiviteter.

**Slutsatser:** Majoriteten av barnens uppfattning var att de är delaktiga i dagliga aktiviteter i hög grad och att de inte upplever några hinder för att delta. Resultatet bör tolkas med försiktighet och det är inte möjligt att generalisera resultatet, eftersom urvalet är litet och instrumentet är under utveckling.

**Nyckelord:** Arbetsterapi, Låg- och medelinkomstland, Picture my participation, Subsahariska Afrika

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## **Abbreviations**

ACPF – African Child Policy Forum

AOTA – American Occupational Therapy Association

CIOMS – Council for International Organizations of Medical Sciences

CRC – Convention on the Rights of the Child

CRPD – Conventions on the Rights of Persons with Disabilities

ICF – International Classification of Functioning, disability and health

ILO – International Labour Organization

LMIC – Low and Middle Income Country

MOHO – Model of Human Occupation

UN – United Nations

UNCT – United Nations Country Team

UNICEF - United Nations Children's Fund

WHO – World Health Organization

## **Introduction**

The Convention on the Rights of the Child [CRC] demonstrated the importance of every child's right to express themselves and have their thoughts and opinions respected (United Nations [UN], 1989). Children with disabilities who live in low and middle income countries' [LMIC] perceptions of participation in everyday activities has not been represented in research (Lygnegård, Donohue, Bornman, Granlund & Huss, 2013). Instead, the focus has been on the parent perspective and this may lead to misunderstandings (Irwin & Johnson, 2005). For example, the child may have a different perception of a situation than the parents (Docherty & Sandelowski, 1999). Lygnegård et. al. (2013) identified the need for more research focusing on describing the perspective of children with intellectual disabilities. Without knowing the child's opinion of their participation in everyday activities the interventions and support given to the child might be inaccurate (Lygnegård et al., 2013).

Globally, people with intellectual disabilities are one of the most marginalized groups and one common difficulty is limited access to community life (World Health Organization [WHO], 2011). Persons with disabilities often experience participation restriction (Bailey, Broddy, Briscoe & Morris, 2014), for example regarding participation in activities in everyday life. Difficult activities may for instance be eating or socializing with other children (Pendzick & Demi, 2009). The Occupational Therapy theory Model of Human Occupation [MOHO] demonstrates the importance of participation in relation to well-being (Kielhofner, 2008).

The expectation for this thesis was that children with intellectual disabilities would be able to express their opinion on their participation in everyday life activities. During the same time as this thesis was carried out, another thesis with a similar aim was made, which was focused on children aged 13-17. This thesis was focused on children aged 8-12, to cover a larger group of children. The results will hopefully be of use for occupational therapists working in this setting, as well as give an insight into the situation of children living with a disability in LMIC. This insight can be used in the professional meeting with persons from countries with similar conditions as Ethiopia.

## **Background**

### **Ethiopia and other low and middle income countries**

Ethiopia is located in the Horn of Africa and constitutes of an area of 1,063,652 square kilometers. Ethiopia had a population of approximately 88,955,000 people in 2014 (Ethiopia, 2015), of which 17 % lived in urban areas. In the year 2011, 43 % of the Ethiopian population were aged under 15. The number of persons with disabilities in the country was estimated to be around 15 million (WHO, 2011), of these 95 % were living in poverty (International Labour Organization [ILO], 2013). Ethiopia is listed as a low income country and 30,7 % of the population is living on less than one USD a day (WHO, 2014).

There is a relationship between poverty and disability which is especially significant in LMIC. In these countries the poverty is high and the resources scarce in relation to the people's needs (Inclusion International, 2006). Gona, Mung'ala-Odera, Newton and Hartley (2011) states that "poverty leads to disability and disability likewise leads to poverty" (p. 181). Poverty, together with disease and malnutrition are factors that affect the prevalence of disability (Bines & Lei, 2007). Children growing up in a poverty setting can be exposed to several risks, such as school difficulties, social and physical insecurity as well as starvation (Walker et al., 2007). Kielhofner

(2008) emphasize that economic and political factors negatively influence the possibility to participate in society, including education. Children with disabilities often have special needs and these needs are not always met in LMIC. The present situation in LMIC contributes to many families including children with disabilities not having the economic resources to finance rehabilitation, health care and transportation to and from health care sites (Lygnegård et al., 2013). Another factor affecting the access to services, including rehabilitation, is that the majority of persons with disabilities in Ethiopia are living in rural areas (ILO, 2013).

According to United Nations Country Team [UNCT] (2011) there is no existing social protection plan in Ethiopia. The health care services are insufficient and of low standard (Girma et al., 2007). In 2013, an overview of in which countries in Africa where occupational therapy was available was published, in which Ethiopia was not included (Béguin, 2013). In 2009, there was a plan for developing the rehabilitation for persons with disabilities in Ethiopia that had not yet been effectively put into action in 2009 (Lewis, 2009). There were also some developed strategies on how to work with inclusion of persons with disabilities, for example teacher training focusing on inclusion (Bines & Lei, 2007). Ethiopia has ratified the CRC (United Nations Children's Fund [UNICEF], 2005), and by doing this they agreed to take responsibility to protect children from discrimination. The CRC describes every child's right to live a good life, this includes not being discriminated, due to disability or any other reason. Article 23 states that children with disabilities have the right to the support and care they need, as well as all the other rights mentioned in the CRC, to be able to live an independent and complete life (UN, 1989).

WHO (2011) states that the data on the numbers of children with disabilities in Ethiopia who attended school is not completely reliable. There are educational programs for special educational teachers at Addis Ababa University, but in 2011 there were not enough training posts to ensure education for all children with special needs. The number of special classes for children with disabilities in the ordinary schools are increasing. In 2007 there were 285 classes of this kind compared with 42 classes ten years earlier (WHO, 2011). This development is in line with what the government is striving for in their strategy for inclusion of persons with disabilities (Lewis, 2009).

### Intellectual disabilities

Impairments due to intellectual disabilities can for example be poor memory, communication limitations, attention problems, slow learning, difficulties with judgement, categorization, abstraction, problem solving and knowing how to start and keep up with tasks. All these difficulties are examples of skills used to participate in activities in everyday life. An intellectual disability impacts the process of developing performance skills and patterns related to engaging in appropriate occupations for the age group (Pendzick & Demi, 2009). MOHO describes that during the early years of life, a foundation for the adult occupational participation in the areas habituation, volition and performance capacity is developed (Kielhofner, 2008). Examples of health conditions in which intellectual disability may be present are Down's syndrome, Williams syndrome, fetal alcohol syndrome and fragile X syndrome (Pendzick & Demi, 2009). Research has shown that it is common that intellectual disabilities are inheritable (David et al., 2014).

People with intellectual disabilities are believed to be the largest group of people with impairments in Africa and globally, this is one of the most marginalized groups. Restrictions for persons with disabilities include for instance limited access to community life, education,



and health-care (WHO, 2011). People with intellectual disabilities may experience social exclusion to a higher degree than people without a disability. This is proved to be intensified in poor contexts, as in some parts of Africa (Inclusion International, 2006). The International Classification of Functioning, disability and health [ICF] (WHO, 2001), as well as MOHO, recognizes that a person's health condition may affect the participation in everyday life. Roles are defined by who we are as persons and how we act in relation to others and are identified both by the environment and by the person themselves. Disability has been found to affect current and future roles. For example, a person may be given a role that does not suite their own perceptions or lose roles that are perceived as important (Kielhofner, 2008). It has been shown that children with disabilities start and participate in school to a lower degree than children without disabilities (Filmer, 2008; WHO, 2011). Children with an intellectual disability combined with other disabilities are part of the group that is least likely to attend school (African Child Policy Forum [ACPF], 2011). Specialized services, such as mental health services and support in schools, are inadequate or absent for persons with an intellectual disability (Adnams, 2010). Kielhofner (2008) describes pupil as an important role during childhood and that roles have an impact on an individual's personality. Therefore, children who do not have the role as pupils, are negatively affected in routines that are important for the future development and activity participation (Kielhofner, 2008).

It is common that the knowledge of intellectual disability is not widely spread in LMIC, which causes misinterpretations about disabilities (Lygnegård et al., 2013). In MOHO, it is mentioned that in many cultures, persons with disabilities are marginalized (Kielhofner, 2008). Descriptions of beliefs that an intellectual disability is caused by witchcraft or divine retribution have been found in several African countries (Lygnegård et al., 2013) and other LMIC. Research findings describe how some mothers of children with disabilities searched for different ways to "cure" the child, because they saw the child's disability as something temporary (Maloni et al., 2010). Collectively, these beliefs may lead to severe consequences for the affected group. The child may for instance be hidden or physically abused by their peers (Lygnegård et al., 2013). These findings are in line with what Kielhofner (2008) states in MOHO, that children with disabilities may experience fewer possibilities to develop their occupational performance. For persons with disabilities, the surrounding physical and social environment may be a barrier to participation (Kielhofner, 2008).

## Activity and participation

Activity is defined as performing an action or a task (WHO, 2001). In the Occupational Therapy Practice Framework II, activity is described as something a person does to occupy herself (American Occupational Therapy Association [AOTA], 2008). Kielhofner (2008) describes activities in daily living as characteristic tasks essential for taking care of oneself, for example eating and performing household tasks. Engagement in daily activities is a means for satisfying human needs, such as enjoyment and participation in the society. Engagement in activities in everyday life is also giving meaning to life and promotes good health (AOTA, 2008; Kielhofner, 2008). Participation is defined in ICF as "involvement in a life situation" (WHO, 2001, p. 10). ICF also describes the concepts activity limitation and participation restriction. Activity limitation is described as difficulties in the performance of an activity that the individual encounter. Participation restriction can emerge in everyday situations, as difficulties the individual experience in her involvement in an activity (WHO, 2001). Occupational therapy services are used to promote health and well-being as well as reduce several risks, for example activity limitation and participation restrictions (AOTA, 2008). According to MOHO children

who participate in productive activities during the childhood learn to take responsibility. The volition to engage in productive activities in the future is strengthened and thereby also the occupational participation is increased (Kielhofner, 2008).

The CRC states that every child has the right to participate in play and other recreational activities (UN, 1989). Kielhofner (2008) describes play as young children's main occupation as well as an important part of the development and participation. The principles of the Conventions on the Rights of Persons with Disabilities [CRPD] include full participation in the society as well as equality regarding opportunities and accessibility (UN, 2006). In an occupational therapy context participation can be described as engagement in everyday activities that we wish to or want to take part in. Several components may influence our engagement in activities and which activities we choose to take part in. These components are habituation, volition, performance capacity and the surrounding environment. The components influence the participation in activities and can be either limiting or enabling. Participation in activities may be changed by a disability, but does not have to be limited if the environment offers the right support (Kielhofner, 2008). An environment that is positive and allowing enables the child or adolescent with an intellectual disability to participate in school, be more independent and develop personal relationships (Pendzick & Demi, 2009). ICF and MOHO states that characteristics of the person, as well as the surrounding environment, may be a barrier or a facilitator to participation and engaging in activities (Kielhofner, 2008; WHO, 2001).

Bailey et al. (2014) find some challenges for children and youths with disabilities to participate in research. One thing that challenges participation is communication. To help the children and youths with disabilities to participate, non-verbal communication, like photographs, cue cards and drawing, can be used (Bailey et al., 2014). Code & Evans (2008) emphasize the importance of involving children and youths with disabilities in research. In MOHO, it is described that when communicating with persons with disabilities it is important to acknowledge their background, cognitive and emotional status and other important characteristics (Kielhofner, 2008).

Most of the research on intellectual disabilities is made in high-income countries, even though the situation in a low and middle income country is completely different (Townsend, 2011). Historically, the research on the health of young children has been focused on the parent and/or health professional perspective (Irwin & Johnson, 2005) and the children's opinions have not been heard (Lygnegård et al., 2013). MOHO states the importance of participation for every human being to experience well-being (Kielhofner, 2008). It is important to survey the children's own perspective regarding their situation since the understanding of their health otherwise will be incomplete (Irwin & Johnson, 2005), as the perception of the parents do not always correspond with the children's (Docherty & Sandelowski, 1999). It has been shown that young children have the capacity to provide the needed insights into their daily life and health experience. By giving the children a voice towards the public, they may be able to affect their own social situation (Irwin & Johnson, 2005). According to article 12 of CRC every child has the right to express their thoughts on matters that concerns them and to have their opinions respected (UN, 1989). The CRPD argues that the opinions of children with disabilities are to be heard according to their maturity and age, in the same way as all children (UN, 2006). An important aspect in the MOHO is to capture each person's perspective (Kielhofner, 2008). Code and Evans (2008) consider that involving children with a disability in research will highlight the child's own voice and participation.

## **Aim**

To describe how children aged 8-12 with an intellectual disability living in Ethiopia perceive their situation regarding participation in activities in everyday life.

## **Questions**

1. Which activities do the children participate in and which activities do they not participate in?
2. Which activities do the children score as most important?
3. How involved are the children in the activities they score as most important on a group level?
4. Which factors hinder or facilitate participation in activities?

## Material and method

### Study design

A descriptive design can be used to chart a population and therefore a descriptive design with a quantitative approach has been used to collect information (Kristensson, 2014). The descriptive design has been chosen to provide a quantitative description of the children's opinion on their participation in everyday activities. The data have been collected using the interview instrument "Picture my participation," which is under development in association with UNICEF (Willis, Imms, Granlund, Bornman & Elliott, 2015). The study design has been chosen as "Picture my participation" was considered appropriate to use to answer the aim and questions of the thesis. "Picture my participation" is an instrument that gathers quantitative data.

### Sampling procedure

The participants have been gathered using non-probability consecutive sampling, meaning that the first undecided numbers of participants who coincided with the criteria was recruited (Kristensson, 2014). The sampling was made at a center for children with intellectual disabilities in a big city in Ethiopia. The center offers services such as early intervention, education and vocational training. The purposes of the services are, inter alia, to enable children with intellectual disabilities to be integrated in the society, and to provide them with the opportunity to develop their personalities and abilities (A. Mekonnen, personal communication, February 29, 2016). Inclusion criteria were that the child had to be between eight to twelve years of age, have an intellectual disability, and be able to understand and follow instructions in Amharic, the "working" language in Ethiopia (Ethiopia, 2015).

The sample was gathered in several steps. First, the coordinator of the center was informed of the purpose and process in an information letter, see Appendix 1, and gave approval to conduct the project. The coordinator gave the authors the advice to assemble children from different classes. Each class with children between eight and twelve were visited by the authors. The teachers were informed about the interviews and asked to recommend some children to participate, based on the inclusion criteria. In total, 16 names were collected and given to the coordinator. The coordinator asked the teachers to call the caregivers and ask them to come to the school to get information and, if they agreed to their child's participation, sign the consent form. The information was given verbally and in writing. The number of caregivers and children who signed the consent form were 16. After being signed, the consent forms were collected and kept safe.

Three cases of non-response were existent. One child was not able to answer any of the questions, one interview was disrupted after prioritizing the three most important activities and the third child answered the first nine questions about frequency of involvement. None of the three children were able to talk. The mean age of the participants were 11 years old and there were four male and eleven female participants.

### Participants

The children had limitations in differing degrees regarding intellectual functioning and adaptive behaviors. Examples of the limitations were learning, problem-solving, interacting with other people, self-care and communication. Despite having the limitations the children were able to communicate with others on their own level, some using words and others using

pictures as support. These limitations were due to a slower development compared to other children of the same age. A common diagnosis at the center was Down's syndrome (A. Mekonnen, personal communication, December 6, 2015).

## Data collection

In total, 15 interviews were conducted, with one participant per interview. The interviews were conducted in separate rooms at the center. The first four interviews were held in one room with many windows and a lot of noise could be heard. The rest of the interviews were conducted in a room with small windows high up on the walls and not as many sounds. Kristensson (2014) describes the best place for the interview as a separate room where the risk of disturbance is small. The interviews lasted between 20 minutes and one hour, depending on the child's ability to understand the instructions, rank and communicate. During the interviews, an interpreter was used to overcome the language barrier between English and Amharic. A teacher or caregiver could attend during the interview if there were any special circumstances. During the interview with the child that did not answer any of the questions a teacher was present. Both authors of the thesis were present during all interviews. One was asking the questions and the other took notes and listed the answers.

## Instrument for data collection

The data were collected using the measurement instrument Picture my participation, which is designed as a structured interview. Extract from the instrument can be found in Appendix 2. This tool is under development and is adapted to be used in interviews with children with disabilities, living in LMIC. There were some pre-written quotes and questions in the interview schedule for the interviewer to say. In the parts where there were not, quotes and questions were created prior to the interviews and some of these are mentioned below. The questions were created with consideration to the children's ability to communicate. Kielhofner (2008) stresses the importance of a client-centered practice, which includes communicating with people on their level. The instrument is developed with the use of ICF and CRC (Willis et al., 2015). Picture my participation is described in the interview schedule as a self-report tool that aims to enable the child to describe participation in different life areas, such as school and home, using pictures. The usage of pictures during the interview supports the child during the assessment. The tool can be used to describe the child's participation, as well as factors that are facilitating or hindering participation (Willis et al., 2015).

Prior to starting the interview preparations were made and the material was set up. The information letter was read to the child by the translator and the child gave his/her confirmation that he/she understood the information and gave their consent to participate again. The interview was thereafter conducted in five steps:

1. The first step aimed to introduce the measuring tool to the child. This was done by reading a pre-written text from the interview schedule. The text describes the aim of the interview and that there are no right or wrong answers.
2. In this step information about the participation in activities and the frequency of participation was gathered. This was done using pictures of children participating in activities and a frequency table. The frequency table had six possible answering alternatives ("always," "sometimes," "not really" and "never", as well as "N/A" and "unsure or no answer," see Appendix 2). The definition of "N/A" was "not relevant to the child." This was explained to the child by saying "This paper shows different levels of how often you do something. If you do it

always, sometimes, not really or never,” at the same time as pointing at the answering alternatives on the table. In the cases where none of the mentioned alternatives were suitable, the alternatives “N/A” or “Unsure or no answer” could be chosen. If “N/A” or “Unsure or no answers” were listed as the answer, it was interpreted as non-response. An explanation that the child was going to be shown some drawings were given, by saying the following, “I am going to show you some drawings of children doing different things. I would like to know if you do these things as well. Do you understand?”. The number of activities were 19, but since the number 8 was missing it started on 1 and ended on 20. Each activity was presented to the child by showing the picture and asking “How often do you ...?”. Examples of questions asked to the children was “How often do you take care of yourself? Put on clothes, brush your teeth and brush your hair?”, “How often do you clean or do laundry at home?” and “How often do you go to the shop or do errands at the market?”, see Appendix 2. After each question the child was asked to place the picture of the activity below the answer that was most suitable. In the cases the child could not understand the concept of the table an oral answer was sufficient. If necessary, the answering alternatives was presented again. The answers were listed on the scoring sheet after each question was answered.

3. In step three the child was asked to prioritize the three activities that were most important to the child. This was done by reading a pre-written text from the interview schedule. Thereafter the child chose three cards and placed them on the side. The chosen activities were written down on the scoring sheet, see Appendix 2.

4. Step four aimed to understand the child’s involvement in the three activities he/she scored as most important in step 3. This was introduced by saying, “I would like to understand how involved you are in these three activities.” The “Level of involvement” table was used, which consists of 5 possible answers (“very,” “somewhat,” “not,” “N/A” and “unsure or no answer”), see Appendix 2. The levels are clarified by pictures and were explained to the child by reading the pre-written text in the interview schedule. The child was asked to place the activities below the most suitable alternative by asking the question, “How involved are you in...?”. The answers were listed on the scoring sheet.

5. The last step focused on listing the barriers and facilitators to participating in the three activities he/she scored as most important. Barriers and facilitators could be both environmental and personal factors. The child was asked the pre-written question from the interview schedule. Thereafter the following question was asked for every factor at the same time as the drawing representing the factor was showed, “Does ... [factor] make it easier or harder for you to ... [activity]?”. There were 4 possible answering alternatives (“Facilitator,” “Barrier,” “Neutral” and “N/A”) as well as one added by the authors (“unsure or no answer”). This was added because some participants did not have an answer or was unsure and on every other question this answering alternative was possible. The responses were listed on the scoring sheet, see Appendix 2.

### Validity and reliability

The data collection instrument Picture my participation is under development (Willis et al., 2015) and has therefore not been used in research or in a clinical setting nor tested for validity and reliability yet. A test for reliability is ongoing and it is being tested in researching projects. A part of assuring the validity of the results was to use a data collection instrument that contained questions that answered to the aim and questions of the thesis. This is a way to avoid measurement bias (Kristensson, 2014).

## Data analysis

The data analysis has been made using descriptive statistics in IBM SPSS Statistics (Version 21) and Microsoft Excel 2016. Relevant descriptive calculations were made in SPSS. Microsoft Excel 2016 was used to create tables and diagrams.

Frequency of involvement could be scored from 4 to 1, with 4 representing Always, 3 Sometimes, et cetera, see Table 1. To present which activities the children prioritize as most important a table was made. Level of involvement could be scored from 3 to 1, see Table 2. A total sum for every child's involvement was calculated by adding up the score for every activity. The maximum sum was nine and the minimum was three. Nine represented a high level of involvement and three a participation restriction and a low level of involvement. Thereafter median, mode and range were calculated in SPSS.

**Table 1.** Scoring: frequency of involvement

Score	Level
4	Always
3	Sometimes
2	Not really
1	Never

**Table 2.** Scoring: Level of involvement

Score	Level
3	Very involved
2	Somewhat involved
1	Minimally involved

All factors could be rated by the participants as either a barrier or a facilitator. The factors were Services and policies, Physical environment, Social environment, Family attitudes, Community attitudes, Beliefs/value systems in the society, and Personal factors. Every child rated all of the factors in relation to the three activities that he/she had prioritized as most important. The mode for each child's ratings in every factor was used to decide if the factor was perceived as a barrier or facilitator for the child. In every factor, the number of children who perceived it as a facilitator or barrier was calculated. Thereafter, the numbers were compiled in a bar chart.

## Ethical considerations

Prior to the interview the form "Ethical Considerations for Student's Thesis" was completed and approved by the supervisor. The coordinator of the center had given her approval for conducting a thesis at the center.

When performing research in a low and middle income country there are some ethical considerations to respect, among these are to show respect for the existing community and the culture (Hyder, Rattani, Krubiner, Bachani & Tran, 2014). Respect was shown through adjusting the times of the interviews. For example, no interviews were held during tea and lunch time, which are routines that are present at the center. Another important aspect was to make sure that the community benefitted from the results in some way (Council for International Organizations of Medical Sciences [CIOMS], 2002; Creswell, 2014). The result of this thesis will be shared with the staff at the center, so that they can use this knowledge when working with the children. The caregivers have been given information about how to find the results after the thesis is finished, so that if they are interested they are able to take part of it. The possibilities for the parents to read and understand the thesis is limited, as it is written in English. Some parents were illiterate or did not understand English.

It is particularly important to take ethical aspects into consideration when a study involves children, as children are vulnerable (Flewitt, 2005) and their ability to give informed assent may be limited (CIOMS, 2002). Therefore, several aspects must be taken into consideration. One of these are that the aim is to gather knowledge that is relevant to the situation of the children. This thesis aimed to describe how children aged 8-12 with an intellectual disability perceive their situation regarding participation in activities. The child had to give assent and the caregiver of the child had to give consent that the child could participate in the interviews (CIOMS, 2002). One important ethical aspect to take into consideration was that the confidentiality of the participants was secured during the process and when the results were presented (Creswell, 2014). The confidentiality was assured by not using the names in the data analysis and result as well as by storing all sensitive information on an encrypted hard drive. The interpreter who was used during the interviews were informed of the importance of secrecy regarding the information from the interviews, and signed a secrecy form before the interviews, see Appendix 3.

The participants and their caregivers were given an information letter before the interviews, with information regarding their rights, see Appendices 4 and 5. The information letter contained a short description of the background and aim of the thesis and information on who will have access to the material. Information that the participation is voluntary and that a participant can choose to end their participation at any time without any reason or negative consequences was also given (Creswell, 2014). This information was adapted to the recipients (Kristensson, 2014). Pictures were used in the information letter to the children to simplify the understanding. In the information to the caregivers a simplified language was used and words that were considered difficult to understand by the authors were avoided, for example professional terminology. The information was given to the caregivers and children in Amharic. The information letter was translated to Amharic by one person and retranslated to English by another person, to secure that the content was still the same after being translated. The information was read to the caregivers who could not read. The children gave their assent and the caregivers gave their consent as they signed the consent form stating their approval of the child's participation prior to the interviews, see Appendix 6. Pictograms was used to facilitate the communication with the child. In other words, a picture of a smiling face symbolized "yes" and a picture of a sad face symbolized "no."



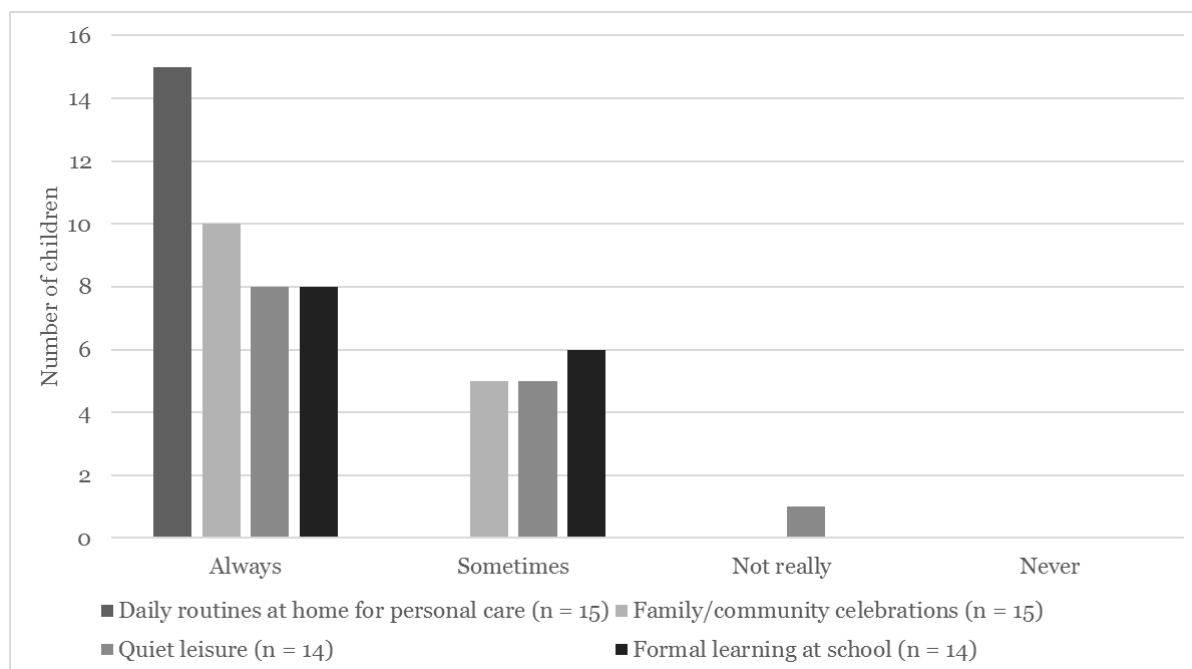
## Results

The results are presented using the questions as headings. The headings are “Which activities do the children participate in and which activities do they not participate in?”, “Which three activities do the children score as most important?”, “How involved are the children in the activities they score as most important on a group level?” and “Which factors hinder or facilitate participation in activities?”.

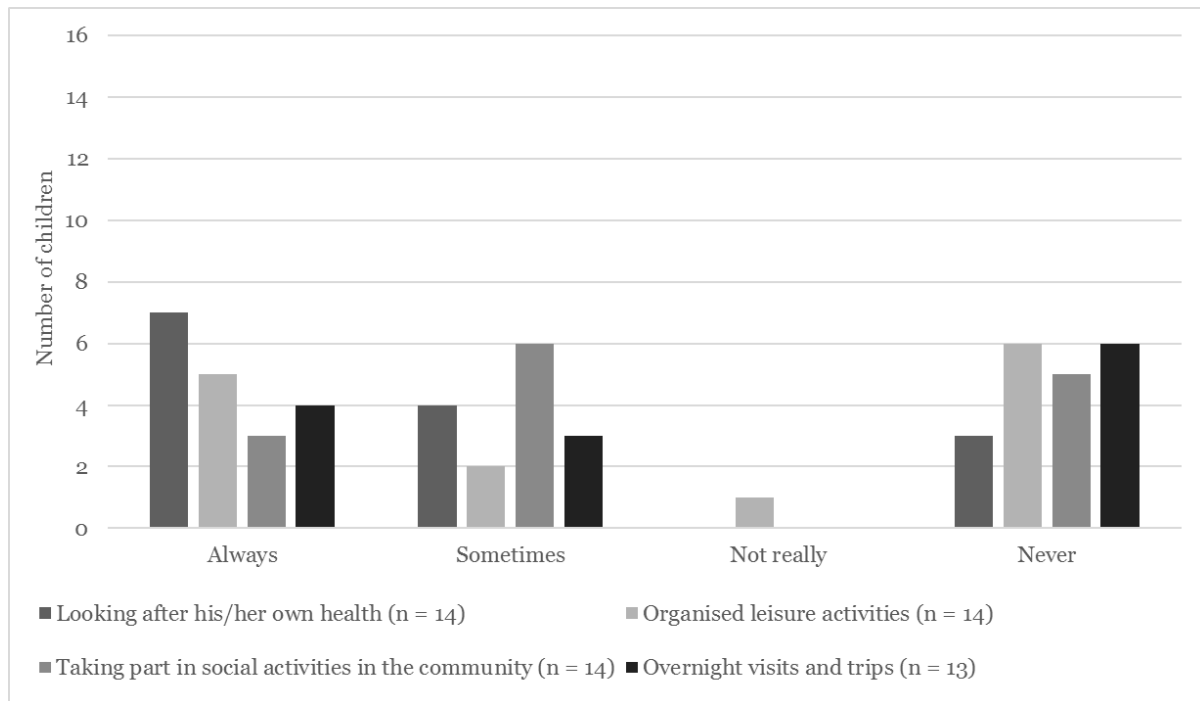
Describing texts, frequency tables and appropriate diagrams are used to show the results. The results are presented in absolute numbers, since the sample size was small ( $n = 15$ ). Eljertsson (2012) strongly recommends absolute numbers to be used when presenting results if the sample size is smaller than 50. If relative numbers are used, the results could potentially be misleading.

### Which activities do the children participate in and which activities do they not participate in?

The frequency of involvement is presented in the four activities that the highest frequency of children rated as doing “Always” and “Never,” respectively. The activities the highest frequency of children rated as “Always” include Daily routines at home for personal care, Family/community celebrations, Quiet leisure, and Formal learning at school are shown in Figure 1. The activities rated as “Never” by the highest frequency of children include Looking after his/her own health, Organised leisure activities, Taking part in social activities in the community, and Overnight visits and trips are shown in Figure 2.



**Figure 1.** How often the children participate in the four activities that was rated as being performed “Always” by the highest frequency of children ( $n = 15$ ).



**Figure 2.** How often the children participate in the four activities that was rated as being performed “Never” by the highest frequency of children (n = 15).

### Which activities do the children score as most important?

Table 3 shows the activities the children prioritized as most important. The activities the children prioritized as most important had a big variation. There were 17 different activities that was prioritized as most important by one to five children, see Table 3. The three top-prioritized activities were; Quiet leisure, Shopping and errands, and Getting together with other children in the community.

**Table 3.** The activities the children scored as most important (n = 14)

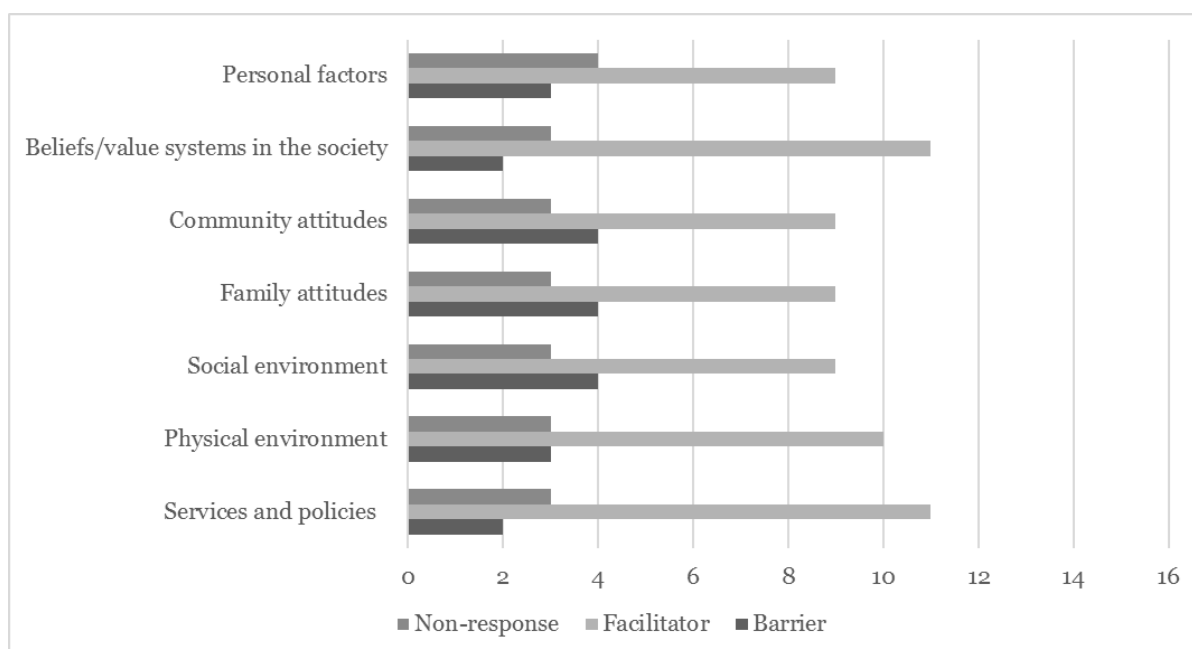
Most important activities	Number of children
Quiet leisure	5
Shopping and errands	5
Getting together with other children in the community	4
Looking after his/her own health	3
Meal preparation with or for the family	3
Organised leisure activities	3
Religious and spiritual gathering and activities	3
Formal learning at school	3
Family mealtime	2
Taking part in social activities in the community	2
Visit health care center	2
Paid and unpaid employment	2
Daily routines at home for personal care	1
Gathering daily necessities for the family	1
Taking care of other family members	1
Family/community celebrations	1
Overnight visit and trips	1

How involved are the children in the activities they score as most important on a group level?

The median of involvement in the most important activities as well as the mode was 8 (n = 13). The maximum score was 9 and the minimum score was 3, with 9 representing participation and 3 participation restriction. The lowest score rated by the children was 6 and the highest 9.

Which factors hinder or facilitate participation in activities?

Every child rated different factors as either hindering or facilitating the three activities they prioritized as most important, see Figure 3. The factors that the highest frequency of children (n = 4) rated as a barrier was Community attitudes, Family attitudes and Social environment. Beliefs/value systems in the society, and Services and policies was ranked by the highest number of children (n = 11) as facilitators.



**Figure 3.** Frequency of barriers and facilitators in the top-prioritized activities (n = 13).

## Discussion

### Method

#### Study design

The chosen study design was the most appropriate for answering the aim of this thesis, as the aim was to describe how children aged 8-12 with an intellectual disability living in Ethiopia perceive their situation regarding participation in activities in everyday life. Kristensson (2014) states that a descriptive design is to be used when describing a population. The authors experienced that the study design was suitable for the aim of the thesis, as that the aim was answered as well as all the questions.

Other study designs that could have been used to answer the aim in a suitable way are interviews with a qualitative approach or mixed method design. A qualitative approach would have given a more detailed description of the children's perception (Kristensson, 2014). A mixed method could have been useful as quantitative data can be combined with qualitative data to give more depth to the results (Creswell, 2014).

#### Sampling procedure

Non-probability consecutive sampling was used to gather the participants for the thesis, meaning that the first persons who corresponded with the inclusion criteria during a specific period of time were asked to participate (Kristensson, 2014). The authors perceived this sampling method as suitable for the purpose of this thesis, since the number of participants were not specified prior to the sampling but a time limit for the sampling existed. It was also appropriate because the parents' consent was needed for the children to participate in the interviews. If the parents of one child disapproved another child could be asked.

The final number of participants was 15. To be able to generalize the results of the thesis in a valid way, a higher number of participants would have been needed (Kristensson, 2014). The inclusion criteria might have had an impact on the internal validity of the results. It is hard to generalize the results to all children with intellectual disabilities living in Ethiopia, because one of the criteria was that the children had to be able to understand instructions and communicate. Limitations in communication skills are common in this population (Pendzick & Demi, 2009), and also a common reason for participation restriction (Batorowicz, McDougall & Shepherd, 2006).

There were three cases of non-response. One child was not able to answer any questions and two interviews were disrupted. The reason for the non-response was that the children did not have the ability to understand instructions and communicate, which was part of the inclusion criteria. This is supported by Bailey et al. (2014) who state that communication limitations may challenge the participation of children with disabilities in research. The reason the children who were not able to communicate were chosen as appropriate participants by the teachers may be inadequate communication between the authors and the teachers, due to the language barrier, when collecting the names of potential participants. To avoid the miscommunication, the authors could have been even clearer on the inclusion criteria or used a translator when communicating with the teachers. There was a risk that the teachers recommended children who had a higher performance capacity. This may have influenced that the results showed that many children participate in everyday activities.

The authors believe that the children felt special when being chosen to participate in the interviews, which was perceived as something positive. There is a risk that the children participating in the interviews were told to participate by their parents or teachers, or that they had the feeling they did not have any other choice than to participate. This may have been an even larger issue with the children who were not able to communicate. The authors cannot be sure if this was the case as the sampling procedure was not witnessed during the situation when the children were asked to participate and sign the consent form. Information that participation in the interviews was completely voluntary was given to the children, parents and coordinator of the center. Right before the interview, the information letter was read to the child and the child was asked again if he/she wanted to participate in the interviews. In this situation, it may have been hard for the child to decline participation, as there were three adults present in the room. If the child felt obliged to participate in the interviews, the authors believe that their answers may not be completely valid. There is a risk that the children gave any answer to get through the interview as fast as possible. Another risk may be that they answered what they thought the authors wanted them to answer. These factors may have affected the internal validity of the thesis negatively.

### Data collection

Both authors of the thesis and the translator were present during all the interviews. One of the authors performed the interviews and the other listed the answers on the scoring sheet. The tasks during the interviews were alternated between the authors. The authors believe this may have secured that the correct questions were asked and the correct answers were listed. It may have improved the reliability of the results, as reliability includes that the results are the same no matter who conducts the test (Kristensson, 2014). The reliability may also have been affected negatively because of the use of an interpreter, as the authors do not know if the interpreter translated in the same way during every interview. When uncertainty occurred during the interview the authors perceived it as positive to be able to discuss and solve the problem right away. On the other hand, it may have been negative if the child felt unsecure with a lot of people in the room, and may in that case have had an impact on the answers. During the interviews, a clear power relationship existed, the interviewer always had the upper hand (Kristensson, 2014). With three persons in the room, the authors perceived the power relationship to be even stronger than if it had only been an interviewer and the child.

The interviews were conducted in two different rooms. The first room was filled with many different stimuli. It was clear to the authors that the children easily got distracted and concentrated on the happenings outside instead of on the interview. The environment in the second room had fewer stimuli. The authors perceived that the children were more concentrated on the interviews in this room. This perception is strengthened by Kristensson (2014), who describes that for the best outcome of the interview, the environment should be calm and safe. The environment in the room affects the person in different ways (Kielhofner, 2008), and therefore an environment that affects the person to feel safe was important during the interviews. Another factor that the authors noticed influenced the concentration of the child, was how long the interview lasted. During several interviews the children got tired, which may have influenced the answers and the internal validity of the results. The reason the children got tired may have been that they did not fully understand the questions and concepts in the instrument. The authors suggest that the instrument should be simplified, to facilitate the usage with this population.

The consent forms and the information letters to the parents and the children were translated by an interpreter with previous experience of translating between English and Amharic. To ensure that the information letters and consent forms had the same content after being translated, a person with good knowledge in both English and Amharic retranslated the documents. The retranslation showed that the translation was close to word-for-word. The reason for this may be that the translator had previous experience in translating documents.

The person who translated had good knowledge in English, because he studied English at university level, and his native language is Amharic. As the authors do not speak Amharic, it was not possible to verify that what the translator said in Amharic correspond with what the authors said in English. For example, the translator might have explained more than the authors did regarding concepts in the instrument that was difficult for the children to understand. An example is that the concept “Services and policies” may have been explained in a way that the authors do not know of. That the thesis consists of quantitative interviews, may have made it easier for the translator to interpret, as none of the answers from the children needed to be translated word-for-word to English. This may ensure that the answers are more accurate. The use of the instrument would have been more simple if the material, for example the tables, were in the children’s native language as some of the children knew how to read Amharic but not English.

#### Data collection tool

The theoretical framework being used in this thesis is MOHO. In MOHO the importance of participation in everyday activities is described (Kielhofner, 2008), and therefore this measurement instrument was appropriate in relation to the aim. Picture my participation is developed in line with ICF. As MOHO and ICF are similar in a number of ways (Kielhofner, 2008), this also makes the chosen measurement instrument suitable.

As the instrument Picture my participation is under development, this bachelor thesis gives valuable information for future use and continued development. The authors found the instrument to review important aspects regarding the children’s perceptions of their participation in various activities. The authors perceived that the children who had the skills to communicate and categorize understood most of the questions in the instrument. One part of the instrument that was perceived by the authors as easy to understand by the children, was the part where the children were to score their level of involvement in the three top-prioritized activities.

One thing that made the process of the interviews more difficult was that there were not enough instructions on how to conduct the interviews. There was a lot of space for interpretation for the authors, both regarding what should be said during the interviews and the meaning of the pictures. If the results would have been valid, it would not have been reliable, as the questions being asked may have been different between the interviews.

As the introduction was perceived by the authors as long and containing difficult concepts, the children had to listen for several minutes before starting to actively do something. This may be negative, as children with intellectual disabilities may have difficulties concentrating (Pendzick & Demi, 2009). The authors perceived that not all of the children understood the different words and concepts used in the instrument, but none of the children expressed that they did not understand and almost all of the participants answered all of the questions. This may indicate that the children understood, but the reason may also have been that the children

thought that the authors expected a specific answer even though the child was told in the beginning of the interview that there were no right or wrong answers. There is a risk that the children did not want to say that they did not know an answer, or did not understand.

The tables for “Frequency of involvement” and “Level of involvement” were perceived as a bit confusing for the children, by both the authors and the translator. The meaning of the concepts “Always,” “Sometimes” and “Not really” seemed difficult for the children to understand. The answering alternatives “N/A” and “Unsure or no answer” are present on the tables, which have been perceived as confusing by the children when answering the questions.

When asked to sort the pictures below the table, a clear pattern was seen during several interviews. In the beginning they placed the pictures from right to left, starting with placing the first picture below “Always,” the second below “Sometimes,” etcetera, or vertical, placing all the pictures below the same alternative. The children answered verbally, for example, that they did something “Always” and thereafter placed the picture below “Sometimes,” if that was the next alternative in the pattern. When the children were asked the question repeatedly and were showed where the answer they told verbally was on the table they understood the concept and in the rest of the questions they placed the card on the same answering alternative as the answer they gave verbally. The reason for this may be that the children are doing exercises in class where they are sorting cards horizontal or vertical, and that they saw the interview as some kind of game or exercise. Another reason might be that children with intellectual disabilities may have difficulties with categorization (Pendzick & Demi, 2009).

The authors state that it is of importance that the pictures are clear and understandable for the children, and that they are showing the concept they are supposed to symbolize. During the interviews, many children looked at the pictures for a long time before answering the questions. If the pictures were perceived by the children as meaning something other than the real meaning, the answers may not be valid. The authors perceived some of the pictures as easily apprehended by the children and others as meaningless, if not explained to the child. One picture that were perceived as difficult for the children to understand was “Organised leisure activities.” This picture shows a child playing three sports at once; football, basketball and rugby. The authors’ perception was that the children interpreted the picture as playing football, which is something most of the children are doing in Ethiopia, but they do not do it in a team, which is what the picture is supposed to symbolize.

The authors considered that some activities should be added to the instrument, as this would strengthen the content validity (Kristensson, 2014). If activities that the children are participating in are missing in the instrument, the general picture of the participation may be skewed. These activities include transportation, visiting friends and family during daytime, as well as dividing the activity “Getting together with other children in the community” into two different activities; playing with other children in school, and playing with other children outside of school. Several children answered that they play with other children in school but not on their spare time. The authors estimate that the difference is relevant, because in school they were playing with other children with intellectual disabilities and this was not necessarily the case outside of school.

During the prioritizing of the three most important activities the authors observed that several children chose the three pictures that were closest to the child or the ones that looked most intriguing. This may have affected the internal validity of the results. The authors considered

it to be difficult for the children to remember the meaning of 19 different pictures, as it took some time for the authors to learn what the different pictures symbolized.

The concepts in the part where the children were to score factors that hinder or facilitate their participation in the three top-prioritized activities were considered by the authors and the translator as difficult for the children to understand. The factors “Social environment” and “Family attitudes” were perceived as similar, as the children told the same answer on both questions, for example “my mother makes it easier for me to participate.” Some of the pictures that were used during this part of the interview were perceived by the authors as easily understood, while other pictures were meaningless, for example the pictures symbolizing “Services and policies” and “Physical environment.” If indeed the children did not understand the concept of and pictures representing the barriers and facilitators the answers may not have internal validity.

### Data analysis

The data analysis program IBM SPSS Statistics was perceived as challenging by the authors. Therefore, only the basic descriptive statistics were calculated in SPSS and when making the diagrams and tables all the data were exported to Microsoft Excel. This was perceived as simplifying the data analysis. The sample of the thesis was too small to make more profound analysis (Eljertsson, 2012).

When starting to analyze the data, the authors were unsure of how it should be done. The authors got guidance from one of the developers of the instrument on how to compile the data in relation to the aim and questions of the thesis. This facilitated the proceeding data analysis process.

### Result discussion

This thesis investigated how children with intellectual disabilities living in Ethiopia perceive their participation in everyday activities. The results showed that overall, the children are participating in everyday activities in a higher frequency than they do not participate in everyday activities. In the activities that the highest frequency of children answered that they “Always” perform, there were no children who answered that they “Never” did the activities. These activities were categorized in three different activity domains according to ICF; self-care, major life areas and community, social and civic life (WHO, 2001). However, in the activities that the highest number of children answered that they “Never” participated in, there were a number of children that answered that they performed the same activities “Always” or “Sometimes.” These activities were categorized in the activity domains self-care and community, social and civic life. The three activities the children perceived as most important were sorted as community, social and civic life and domestic life, in the ICF domains (WHO, 2001). Further, the results showed that the children in the sample were involved in the activities they scored as most important and generally, they did not experience a lot of barriers to participate in the same activities.

The subject has to be further investigated for it to be possible to make trustworthy conclusions and generalize the results to a broader population. The sample size was too small and relatively homogenous to make any valid conclusions, which is confirmed by Kristensson (2014). The children had similar intellectual disabilities, were from the same city and went to the same school, which made the sample relatively homogenous. Also, the authors’ subjective feeling was that all of the children did not always understand the questions or what they were



supposed to do, as discussed further in the method discussion. With respect to the factors mentioned above, the authors do not consider the results as valid, but as a first statement of the population's perceptions.

The four activities that the highest number of children participated in can be categorized in the ICF activity domains self-care, community, social and civil life and major life areas (WHO, 2001). All of the children reported that they "Always" participated in the activity Daily routines at home for personal care. The authors believe the reason for this may be the routines at school, every morning the children are to tell the class about their morning routine before school. The children also have the possibility to practice activities related to personal care in school. This is similar with findings in a study conducted by Arvidsson, Granlund, Thyberg and Thyberg (2014), which showed that the activities that children with disabilities carried out most frequently was, inter alia, activities related to self-care. Another activity that a high number of children rated as doing "Always" was Quiet leisure, which coincides with findings in a study investigating what kind of leisure activities children with disabilities participate in (Harding et al., 2009). According to MOHO, participating in activities as a child, promotes the future development of occupational participation (Kielhofner, 2008). The authors of this thesis believe that because the children's perception is that they are frequently participating in a large number of activities, their future occupational participation is promoted.

The results show that three of the four activities the highest frequency of children rated most frequently as "Never" participating in were Organised leisure activities, Taking part in social activities in the community, and Overnight visits and trips. This finding is similar to findings in previous research (Arvidsson et al., 2014), which showed that the activities that was listed as least frequently participated in were categorized in the ICF domain community, social and civic life (WHO, 2001). The authors believe the reason why Organised leisure activity was rated as an activity the children did not participate in is that there are no organized sport teams for children in Ethiopia. This activity was ranked as one of the three most important activities by three of the children. It is unsure if the children were interpreting the picture as playing football or playing football in a team.

According to WHO (2011), persons with disabilities often experience limited access to education and community life. This both contradicts and coincides with the findings of this thesis. The results showed that the children's perception is that they participate in the activities Formal learning at school and Family/community celebrations. They did not participate in Taking part in social activities in the community, Organised leisure activities and Overnight visits and trips. These activities are categorized as community, social and civic life, according to ICF (WHO, 2001).

The top-three activities that were prioritized as most important are categorized in the ICF domains domestic life and community, social and civic life (WHO, 2001). The results show a broad variation in which activities the children prioritized as most important. The authors believe that this can be because the children have different interests, which according to MOHO influence which activities a person choose to perform. Which activities that are perceived as most important may also differ in the different ages (Kielhofner, 2008).

An activity that was prioritized as most important by five children was Quiet leisure. A high frequency of children answered that they performed this activity. This coincides with findings

in a study conducted by Arvidsson et al. (2014) that the activities that were scored as most important also were performed often.

The median (8) and mode (8) showed that the children were very involved in the activities they prioritized as most important, on a group level. Both descriptive statistical numbers are high and close to nine, which represent participation. A conclusion of this is that the sample does not suffer from participation restriction, which is described in ICF as a limitation in activity involvement (WHO, 2001). According to Kielhofner (2008) participation in everyday activities promotes health and well-being. Consequently, the sample may experience health and well-being. Though, to know this for sure, further research needs to be made.

The majority of the children rated most of the factors as facilitators. This coincides with findings in a qualitative study, in which the children mentioned more factors that facilitated their participation in leisure activities, than factors hindering their participation (Harding et al., 2009). The authors believe that the results of this thesis may show the actual situation, but there is also a risk that the children answered the questions without fully understanding them or gave the answers they thought the authors were expecting. For example, the children might not have wanted to say that “Services and policies,” for example the government, is a barrier, because it can be seen as controversial to question the government’s work, or they might not know what the government is and what they do. Another factor that may have influenced the results’ validity negatively is that the different factors are difficult constructs, and may include both barriers and facilitators. There is risk that the children mainly speak about the facilitators, instead of the barriers (Harding et al, 2009). Therefore, the authors believe this may be an explanation why the majority of the children rated a higher frequency of the factors as facilitators.

Previous research, in which parents answered questions about barriers and facilitators regarding their child’s participation in the community, show that the environment is perceived as a factor that hinders the participation (Bedell et al., 2013). The authors believe that the reason why this differs from the results in this thesis may be that in Bedell et al.’s study (2013) parents were answering questions about the children’s participation and factors that influence their participation. In this thesis children answered the same kind of questions.

Kielhofner (2008) describes that disability may limit the participation in activities, but if the environment offers sufficient support, for example assistive technology, the participation does not have to be influenced. As the children answered that they participate in activities “Always” or “Sometimes” in a higher frequency than “Never,” and they rated most of the factors as facilitators, a conclusion may be that they receive sufficient support from the environment.

### Importance for Occupational Therapy

As an occupational therapist it is of importance to know that children in a context and culture like Ethiopia feel involved in daily activities, as well as perceive that the physical and social environment supports them. The authors’ preconception was that the result would show participation restriction and that other persons may have the same picture of the situation. Having this conception of the situation may influence the occupational therapist’s operation mode, and as the results of this thesis disprove this conception the operation mode may also change.

Kielhofner (2008) states the importance of integrating the personal factors of the individual, such as habits, perspective and roles, when working with a client. This thesis may give knowledge about the children's perceived participation in everyday activities, which is a good basis for the choice of relevant occupational therapy interventions and in the meeting with the individuals in the population. Also, the prioritization of which activities that are the most important showed a big variation. This indicates the importance of taking each child's interests and perceptions into consideration. This supports Kielhofner's (2008) statements about client-centered practice in occupational therapy.

The data collection instrument used in this thesis can also be used in clinical practice by different professions (Willis et al., 2015), including occupational therapists. The instrument was tested in the thesis and the authors' opinion is that there are some limitations. Hopefully, this will contribute to the further development of the instrument. In this way, the results are of importance for occupational therapists who are going to use it in the future.

There are no occupational therapists working in Ethiopia (Béguin, 2013), with the exception of volunteers from abroad on a temporary basis. There are neither any occupational therapists working at the center where the interviews were conducted for now, previously an occupational trained in Sweden worked there (M. Toporek, personal communication, May 22, 2016). If an occupational therapist were to start working at the center with this population, the working tasks could include interventions to increase participation. For example, in the activities a high frequency of children answered that they "Never" participate in, including Taking part in social activities in the community, and Overnight visits and trips.

### Further research

The authors see a need for more research involving the perception of children with intellectual disabilities. A suggestion for future research in the same area of interest is to conduct qualitative interviews with children with intellectual disabilities about participation in everyday activities. During the quantitative interviews in this thesis some of the children started telling a lot about their everyday life and gave specifics about what they do and how they do it. The authors' opinion is that it would be of interest to capture a picture of their participation more in detail.

Another implication is to continue examining the children's own perception of their participation in everyday activities using a quantitative method, as the existing research is limited (Lygnegård, 2013). As the sample of this thesis was small, a recommendation for coming studies is to have a larger sample, to be able to generalize the results and ensure a higher validity of the results (Kristensson, 2014). To ensure the validity and reliability of the instrument Picture my participation, it needs to be used in more studies in the future.

Participation in activities promotes well-being and health (Kielhofner, 2008). Further studies can investigate this population's perception of health and well-being in relation to participation.

## **Conclusions**

The purpose of the thesis is to describe children with intellectual disabilities' perception of their participation in everyday life activities. The key finding of the thesis is that the results are not considered by the authors as valid. The results showed that the children's perceptions were that they participated in everyday activities in a higher frequency than they did not participate in everyday activities. Further, the children were involved at a high degree in the activities they prioritized as most important, and the results showed that the majority of the children did not perceive that they experienced any barriers to performing those activities.

The results cannot be generalized to a larger population and are to be interpreted with caution, as the sample size is small and relatively homogenous as well as because the instrument is not fully developed. However, the results can be seen as a starting point for further research in this subject.

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## **Appendix 1 – Information letter to the coordinator of the center**

# **Participation in everyday activities**

Participation is defined as being involved in different life situations, for example getting dressed, attending school and interacting with other children. Intellectual disabilities may sometimes lead to restrictions regarding participation in everyday activities.

The United Nation's Convention on the Rights of the Child states that every child has the right to live an independent and complete life and emphasizes that the rights also applies to children with disabilities.

Up to now, most studies has given the parents or health professionals opinions but few studies have described the child's own perspective on participation in everyday activities. It is of great importance that the child's voice is heard to fully understand their situation.

### **Purpose**

To describe how children aged 9<sup>1</sup>-12 with intellectual disabilities perceive their participation in activities in everyday life.

### **Procedure**

The child will be asked to participate in an interview. Information about the interviews will be given orally as well as written. During the interview the child will answer questions about the activities they are participating in, which activities they perceive as most important and if there are any factors that makes it easier or harder to participate in activities. Pictures are used to visualize the different activities. The interviews will take place at the center and take about 30 minutes.

### **Permission of participation**

The participants will be about 10 children between the ages of 9<sup>1</sup> and 12 who attend the center. Participating in the interviews is voluntary and refraining from participation will not have any negative outcomes. The child is free to stop the participation at any time without any reason and this will not affect the child in a negative way.

The results from the interviews will only be used in the thesis and possibly in future research. The results will not be used for any other purpose. The confidentiality will be respected, meaning that what each child has said will not be able to trace back to the person and that unauthorized persons will not take part of any material.

A translator will be used during the interviews to translate between Amharic and English. This person has been informed about the confidentiality and has to sign a contract that he/she will not give out information to unauthorized persons.

For a child to participate in the interview both the child and the parents/legal guardians have to give their approval, either orally or written.

### **Benefits**

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<sup>1</sup> The original plan was to describe the situation of children aged 9-12, but in the sampling process a child aged 8 was recommended by the teachers, without the authors knowing about it.



Hopefully the results from the interviews will contribute to an increased understanding of children's perception on participation in everyday activities. By identifying factors that makes it easier or harder to participate in activities, interventions can be created to increase participation.

### **Presentation of the results**

The final result will be presented in a Bachelor thesis. A printed copy of the thesis will be sent to the center.

**If you have any questions, please contact us.**



Sarah Berger

Phone number:

E-mail: [bergersara@live.se](mailto:bergersara@live.se)











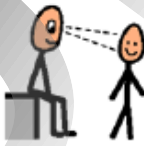

Sandra Andersson

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

## Appendix 2 – Extract from the instrument Picture my participation

Always  (6)	Sometimes  (5)	Not really  (4)	Never  (3)	N/A (2)	Unsure or no answer (1)
1. Daily routines at home for personal care (dressing, choosing clothing, hair care, brushing teeth) Personal care					
6. Cleaning up at home (clothing, house-hold objects, laundry, rubbish, yard work) Cleaning at home					
15. Shopping and errands (market) Shopping					
Very  (5)	Somewhat  (4)	Not  (3)	N/A (2)	Unsure or no answer (1)	

### Appendix 3 – Secrecy form for the translator

#### 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: 12<sup>th</sup> Apr. 2016

Signature: 

Name: Abebe Dantew Debay

Contact information to the students conducting this study:

Sandra Andersson, [sandramaria.andersson00@gmail.com](mailto:sandramaria.andersson00@gmail.com)

Sarah Berger, [bergersara@live.se](mailto:bergersara@live.se)

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

## Appendix 4 – Information letter to the children

# What activities do you participate in?



### What do we want to do?

We would like to have a chat with you about what you are doing during the day and if there is anything that stops you from doing it.



### Why do we want to do it?

Because we would like to know what **you** think.



### Who are participating?

About 10 children aged 9<sup>1</sup> to 12 who just like you attend the center.

### Do you have to participate?

No, not if you don't want to. You can end your participation at any time, without anything bad happening.



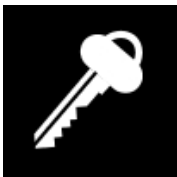
### What will happen?

We will ask you questions about what you do during the day, if you like to do it and if there is anything that makes it easier or harder to do it. You can answer the questions by using pictures.



### Who are asking the questions?

Sarah or Sandra. We don't know Amharic, therefore a translator will be there and help us ask you the question.



### What happens with the answers?

The answers will be kept in a safe place. The answers will only be used in this project and maybe in future research.



### Who will know the answers?

Only Sarah, Sandra and the translator will know what you have answered. Your name will not be written down or mentioned to anyone else.



If you have questions, please talk to us at the center.



Sarah Berger



Sandra Andersson

Supervisor: Elisabeth Elgmark. E-mail: [Elisabeth.Elgmark@ju.se](mailto:Elisabeth.Elgmark@ju.se)

## **Appendix 5 – Information letter to the caregivers**

### **What activities does your child participate in?**

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

We would like to have a chat with your child about what he/she are doing during the day and if there is anything that stops him/her from doing it.

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

Because we would like to know what **your child** thinks. Up to know, most research describes what the parents and care givers think and it is important that the child also can give their perspective.

#### **Who are participating?**

About 10 children aged 9<sup>1</sup> to 12 who attends the center. It is voluntary to participate and the child can end the participation at any time without any reason and without anything bad happening. The services given from the center will not be affected.

For a child to participate in the interview both the child and the parents have to give their approval.

#### **What will happen?**

We will ask the child questions about the activities they are participating in. For example which activities they perceive as most important and if there is anything that makes it easier or harder to do it. The child will be able to answer the questions using pictures.

The interviews will take place on the center. We don't know Amharic and therefore a translator will be used during the interviews.

#### **What happens with the answers?**

The answers will only be used in this project and maybe in future research. The answers will be kept safe and what the child has answered will not be able to trace back to the child, family or center.

#### **Who will know the answers?**

Only the child, Sarah, Sandra and the translator will know what the child has answered. The name of the child will not be written down or mentioned to anyone else. The translator has been informed of this and has to sign a contract that he/she will not give out information to anyone else.

#### **How will the results be presented?**

The final result will be presented in a report. If you wish to take part of the result you may contact the coordinator of the center.

If you have any questions, please contact us at the center.



Sarah Berger

Phone number:



Sandra Andersson

Phone number:

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

## Appendix 6 – Consent form

# Consent form

The caregiver(s) and the child have taken part of the information of the project: *Participation in everyday activities*.

We know that participation is voluntary and that either the child or the caregiver can end the participation at any time without any reason and without anything bad happening.

We have been given the possibility to ask questions and have gotten the answers we need.

**I approve that my child participates in the project**

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Name of the child

---

Place, date

---

Signature Caregiver 1

**I want to participate in the project**

☐

**I do NOT want to participate in the project**

☐

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Signature Child