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Abbreviations

ABA Applied Behavioral Analysis

ADL Activities of daily living

ASD Autism spectrum disorder

IADL Instrumental activities of daily living

ICNA International Child Neurology Association

MFS Minor Field Study

NAC Nehemiah Autism Center

OTARG Occupational Therapy Africa Regional Group

PEOP Person-environment-occupation-participation

SIDA Swedish International Development Agency

WFOT World Federation of Occupational Therapists

Introduction

The author of this bachelor thesis is an Occupational Therapy student from the School of Health Sciences at Jönköping University, Sweden. The author has a burning interest in the potential role of Occupational Therapy in developing countries and has been invited by the Nehemiah Autism Center (NAC) in Addis Ababa, Ethiopia to conduct a Minor Field study (MFS). This study aims to identify the occupational therapy needs at NAC. Research regarding autism spectrum disorder (ASD) in Africa is restrictive and this thesis may provide valuable information regarding this topic (Newton & Chugani, 2013). Future therapists and students are encouraged to read this thesis to assist them in establishing appropriate client-centered research questions and/or project together with the organization.

A part from the MFS, a 12-week placement has been completed in conjunction with participating in a service-learning project at NAC. This has allowed the author to familiarize with the cultural context prior data collection. Occupational therapy is limited in Africa, and this study could potentially supply relevant insights upon the emerging role (Sherry, 2010). Furthermore this thesis may direct occupational therapy participation at NAC and potentially clinically justify funding for the needs identified.

Background

Ethiopia

Ethiopia is located in the middle of the Horn of Africa (SIDA, 2014). Despite that Ethiopia is one of the most resource-rich countries compared to other African nations, it is still recognized as a low-income country with a gross national income per capita of 1,110 USD (Globalis, 2013; World Health Organization, 2013). It has been reported that previous conflicts have slowed down the development of Ethiopia significantly (SIDA, 2014).

The health status of Ethiopians is still profoundly low compared to high-income countries (World Health Organization, 2013). The population of Ethiopia is approximately 92 million, where 44% are under the age of 15 (World Health Organization, 2013). Major challenges in healthcare in Ethiopia is shortage of workforce, lack of funds, poor implementation capacity, and low prevention mother-to-child transmission of diseases (World Health Organization, 2013).

A study distributed surveys to 23 countries across Africa, including Ethiopia, to investigate the capacity and needs on child neurology (Whilmshurst et al., 2011). It concluded that neurology services were lacking in Africa. Barriers included lack of resources; access to facilities for the pediatric population was much limited; and lack in trained individuals. It was also reported that most training programs are overseas. Once trained the individuals tend to not return to their home country. Those who do return may be overwhelmed by the high demands and therefore leave.

The relationship between policy, disability and childhood development

In sub-Sahara Africa child health services have not been made aware to policy makers (Bakare et al., 2009). Lack of awareness may have great consequences to childhood development. Child poverty is closely linked to the denied access of various resources such as social, cultural, physical, environmental, political, and/or economics (Cockburn & Kabubo-Mariara, 2010). Limited government support can interfere establishment of services for children with disabilities (World Health Organization, 2011). Denied or limited access to services may result in high rate of child illness, disability and shorten life-expectancy (Cockburn & Kabubo-Mariara, 2010). This further contributes to a decrease of economic

growth of the country as the population's intellectual and physical potential is reduced by the fundamental deprivations of child poverty.

The Convention Rights of Child state that every child has the right to develop to their fullest (World Health Organization, 2011). In developing countries children are exposed to multiple risk factors that can impact a child's neuro-cognitive development, which further determines the socio-emotional, sensory-motor, and cognitive development (Maulik & Darmstadt, 2009). It has been estimated that 200 million children under the age of the five in Asia and Africa do not reach their cognitive potential (Grantham-McGregor et al., 2007). Accessibility to services, healthcare, and education has a strong impact in addressing these risk factors (World Health Organization, 2012).

The Ethiopian Constitution includes, "the universal right to education, and emphasizes the need to allocate resources and provide assistance to disadvantaged groups (art. 41 & 91), p. 1" (Ministry of Education, 2006). By 2015 the goal is to provide good quality primary education for all citizens of Ethiopia regardless of poverty, ethnic backgrounds, language, gender, learning difficulties and impairments. It has been identified that there is still a gap in providing access to education for all children that includes inopportune learning environments; lack of identification processes; lack of knowledge concerning diversity; and inadequate assessment procedures. This results in the teachers' incapability of meeting the learning needs of the children. Currently existing special schools, such as NAC, have a long waiting list (Ministry of Education, 2006). Only less than 1% of children and students with special needs access primary education.

Without the appropriate early interventions it will limit the opportunity for the child to develop a meaningful participation in adulthood, as well as restricting the caregiver's participation in society. When the rights of children are unmet this puts them and their families at risk for lifetime consequences. There is a great need among children with disabilities to be a part of an inclusive environment.

Autism Spectrum Disorder in Africa

Published reports regarding ASD in Africa is significantly limited (Malcom-Smith, Hoogenhout, Ing, Thomas, & Vries, 2013). Newton & Chugani (2013) report that the epidemiology data regarding the prevalence is non-existent in Africa. Barnevik-Olsson, Gillberg & Fernell (2008) investigated the prevalence of ASD among Somali children in Stockholm County, Sweden and the results showed that the prevalence was three to four times higher compared to other ethnicities. A follow up indicated that the prevalence increased (Barnevik-Olsson, Gillberg, & Fernell, 2010). A study from the United Kingdom reported that children of immigrants from the Caribbean and Africa had the highest frequency of ASD cases compared to other ethnicities (Keen, Reid, & Arnone, 2010). In Addis Ababa there are two schools that cater for approximately 120 children with ASD (Nehemiah Autism Center, 2015a; Nia Foundations- Joy Center, 2015). Addis Ababa has a population of about 3.4 million people (Ethiopia Tourism Organization, 2015). According to a study conducted in Sweden; the prevalence of ASD among children aged 0-17 living in Stockholm county is approximately 1% (Idring et al., 2012). Stockholm County has a population of 2 million (Statistics Sweden, 2013); when reflecting upon these statistics and the previously mentioned studies, it may be concluded that the ASD population in Addis Ababa is much larger than 120 children of 3.4 million people.

ASD is a developmental disorder that influences a person's ability to interact, communicate, and relate socially to others (Case-Smith, 2001; Tonge & Brereton, 2011). It has a neurobiological origin, however the direct causation of ASD is unknown. The functional

prognosis is diverse. Some cases will be independent, need minimal support, or dependent on caregivers. Regarding effective interventions an interdisciplinary approach is encouraged such as speech therapy, behavioral therapy, family support, occupational therapy, and special education programs. ASD is a life-time disorder and symptoms can change, therefore healthcare professions have a continuous role to educate, advise and support clients with ASD and their caregivers (Tonge & Brereton, 2011).

Two systematic surveys and one case-series addressed the features of ASD in Africa (Khan & Hombarume, 1996; Lotter, 1978; Mankoski et al., 2006). There were similar features to western children with ASD reported such as sensory distortion, epilepsy, poor coordination, and hypotonicity. Newton & Chugani (2013) stated that features of ASD in Africa differed from non-African nations: African children with ASD are diagnosed later in life, there is lack of awareness among healthcare workers, symptoms of ASD is seen as a spiritual cause, and majority of cases are non-verbal. A study from Tanzania indicated that 71% cases were nonverbal, compared to developed countries 25% of cases were non-verbal (Mankoski et al., 2006). It is argued that this major difference is due to that only extreme cases are accepted in special education schools attending to children with ASD in African. Children with ASD in Tanzania that have functional language are less likely to be diagnosed. From the case-series that Mankoski et al (2006) conducted showed that 3 children had normal childhood development until diagnosed with severe malaria, thereafter should symptoms of ASD. A relationship between severe malaria and language impairment has been reported in a study from Kenya (Carter, Murira, & Ross, 2003). This may suggest that severe malaria increases the risk to develop ASD. A study showed that co-morbid disorder associated with ASD among African children besides non-verbal is epilepsy and intellectual disability (Belhadi, Mrad, & Halayem, 2008). Intellectual disability made 60% of the cases.

Newton & Chugani (2013) stated that there is no literature regarding the management of ASD in Africa. Access to services is limited to a small group of children who attend at special education schools. In sub-Saharan African countries the lack of resources in the environment interfere with multidisciplinary management of ASD (Bakare et al., 2009). Bakare et al (2009) concluded that ASD awareness among health care workers in Nigeria was limited affecting the management of ASD.

Role of Occupational Therapy

Occupational therapists have an important role in attending to the various challenges experienced by people with ASD for instance dressing and bedtime routines (Ashburner, Rodger, Ziviani, & Jones, 2014; Schaaf & Blanche, 2012). In the United States occupational therapy was ranked second as the most frequently provided service for people diagnosed with ASD, this further highlights the significance of the role (American Occupational Therapy Association, 2008).

Occupational therapy services focus on enhancing participation and performance of activities of daily living (ADLs), education, play, leisure, rest and sleep, instrumental activities of daily living (IADLs) and social participation within the person's environment. The service follows a process which include evaluation, intervention, and assessing the outcomes from the intervention applied (American Occupational Therapy Association, 2008). These services can be provided at individual, organizational, and population level. The evaluation process is needed to gain insight of the client's occupational profile and occupational performance. Thereafter evaluate the enablers and barriers to necessary and valued occupations of the client.

Currently Ethiopia does not have licensed occupational therapists (Occupational Therapy Africa Regional Group, 2015). Thirteen occupational therapists in Africa was interviewed regarding their role as occupational therapists (Sherry, 2010). Six main areas were identified with the role: networking, administration, planning & consulting, capacity-building, hands-on therapy, and advocacy (Sherry, 2010). It was reported by the therapists that in the African context a broader role must be adopted due to the lack of trained occupational therapists residing in the country. They also expressed that they had many different skills, but did not fully master one of them.

Person-environment-occupation-participation Model

Person-environment-occupation-participation model (PEOP-model) is used in occupational therapy practice to improve everyday performance of necessary and valued occupations (Baum & Christiansen, 2005b). It is an evaluation process, which allows the therapist to organize and investigate person and environmental factors that support, enable or restrict the client from participating in activities, tasks, and roles that are meaningful for them. The PEOP-model has four major components: the psychological, physiological, neurobehavioral, cognitive and spiritual aspects of the client (person), what the client needs and want to do (occupations), what occupations the client is doing (performance), and where the client is performing the occupations (environment). The interaction between the client's capacity, their environment, and desired activity leads to occupation performance and participation (see figure 1).

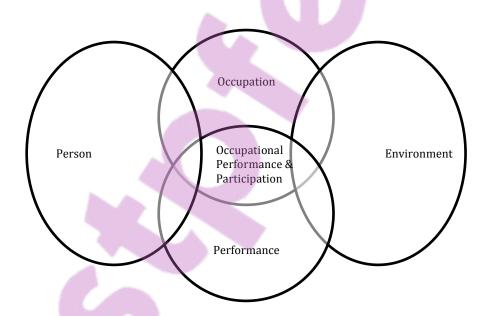


Figure 1: An example of the interaction between the four components of the PEOP-model.

The PEOP-model further stresses that clients naturally want to explore their environment around them and master their interaction with the environment (Baum & Christiansen, 2005b). This ability to master one's interaction with the environment to be able to perform the necessary and desired occupations dictates their self-identity and sense of fulfillment.

The PEOP-model helps the therapist to view the complex interaction between person and environmental factors and further identify which factors support, enable, or restrict the performance of necessary and desired activities of the client. This assists the therapist with

planning client-centered interventions that aim to increase occupational performance and participation of the client furthermore increasing the client's sense of fulfillment.

Assessing the needs of an organization

Addressing occupational performance issues of organizations is an emerging area of practice for occupational therapists (Baum, Bass-Haugen, & Christiansen, 2005). At an organization level the focus may revolve around educating service providers and evaluating the current needs to design appropriate programs and an inclusive environment for children with ASD (American Occupational Therapy Association, 2008). To evaluate the current needs experienced by members of the organization, a needs assessment is most appropriate (Royse, Staton-Tindall, Badger, & Webster, 2009). In occupational therapy terminology needs would be defined as the gap between what the client wants and needs to do and what the client can already do (American Occupational Therapy Association, 2008). A needs assessment relies on internal information about the current situation (Gupta, Sleezer, & Russ-Eft., 2007). It is important to empathize that an organization has a culture of its own where members share values, attitudes, practices and beliefs (Baum & Christiansen, 2005a; Royse et al., 2009). The services provided at an organization can be influenced by many factors, which may include needs of the client(s) change, change of demographics, and perhaps a different financial situation (Royse et al., 2009).

One model that therapists may use to assist them in their evaluation process of an organization is the PEOP-model (Baum et al., 2005). Baum et al. (2005) stated that the PEOP-model is an appropriate framework as it helps the therapist to identify factors related to occupational performance issues experience by an organization. It allows the therapist to recognize enablers and barrier in the environment that impact participation and health. It is stressed that need assessments not should only explore gaps but also existing resources (Timmreck, 2003).

By conducting a needs assessment this could help set achievable goals and further enhance health and well-being among members (Doll, 2010). It is also a helpful tool in assisting with the development and growth of an organization to achieve their goals (Royse et al., 2009). When constructing a needs assessment it is important to address the organization's vision, mission and goals to ensure that the responses are applicable to the concerns expressed by the organization. (Royse et al., 2009). Doll (2010) highlights that a needs assessment is a vital component in identifying the current needs.

Aim

To identify the occupational therapy needs at the Nehemiah Autism Center by completing a needs assessment.

Method

Study design

A mixed-method design has been adopted to gain information from staff and caregivers at NAC. This study used PEOP-model to develop an appropriate needs assessment of the organization. Occupational therapists address multiple factors influencing occupation performance issues within an organization; these factors have a dynamic interaction with each other (Baum & Christiansen, 2005b). This interaction was empathized to identity environmental barriers and enablers to occupation performance. To capture this complexity a mixed method design was most appropriate as it allowed the author to obtain a

comprehensive view of the needs assessed; as well as gain instrumental data concerning place, setting, and context of personal experience (Creswell, 2015). Furthermore by combining quantitative and qualitative data gains a greater understanding regarding the research topic as the strength of one method compensates for the weakness of the other method (Creswell, 2015; Punch, 2013).

Doll (2010) stresses that multiple methods should be used when conducting a needs assessment to gain a comprehensive understanding. Both quantitative and qualitative data has been collected in this study through observations, informal interviews, survey questionnaires and semi-structured interviews. When collecting data for the study the author has followed the situational analysis process of the PEOP-model(Baum et al., 2005). Situational Analysis is defined by Baum & Christiansen (2005) page 569 as, "a process that involves the collection of information and the analysis of factors intrinsic and extrinsic to the individual, the organization or the population to determine the occupational performance issues that will impact the ability to reach client-centered goals." The Situational Analysis will identify strengths, weakness, opportunities, and goals and will help the practitioner choose the appropriate evidence-based intervention to help the client achieve his or her goal." The author has continuously been working through the situational analysis process of the PEOP-model to identify the occupational therapy needs of NAC.

Setting

The first step of the Situational Analysis, *The Collection of Client Information*, was used to thoroughly describe the setting of this study (Baum et al., 2005). The Collection of Client Information was completed through informal interviews, observations, and collecting information through the organization's website; this was documented in a journal by the author. The purpose was to describe the organization, discuss general concerns, and identify the goal of the organization.

Description of the organization

Nehemiah Autism Center is a NGO that was founded June 16th 2011 and is located in Addis Ababa, Ethiopia (Nehemiah Autism Center, 2015b). This is a non-profit and non-government organization licensed by Charities and Societies Agency. Stakeholders of the organization include the director, co-director, administration, teachers, students, and the families to the students. The center provides education and support for children with ASD and their families free of charge. Transportation is also provided for those families who have difficulty transporting their children to school. Currently there are 24 staff members, with a range of various backgrounds such as nurses, teachers, administration and bachelor degree of psychology. Approximately 40 children and their families use the services provided at NAC. Sometimes volunteers are present during school hours.

Activities during a normal school day include playing outside, relaxation, eating, participating in class activities, napping, and toileting. Depending on the student's skills class activities may include completing simple puzzles, stacking blocks, tracing letters, learning the days of the week, and matching cards. NAC has adopted applied behavioral analysis (ABA) for the teaching sessions: one teacher is responsible for two students. NAC has a small playground consisting of carousal, stationary bike and monkey bars. Rarely are group activities arranged, children play individually. Staff members communicate with parents everyday through a communication booklet. Meetings are between the administration and staff members once a month.

From the informal interviews and observations the author found that great area of concerns of the organization included spreading awareness of ASD, funding, intervention planning for each student, and a need for training for staff members and caregivers. Currently eight Ethiopian companies providing funding for NAC. In the future, NAC are hoping to find donors abroad.

Organization's goal

Their focus is to provide education and rehabilitation to as many children with ASD whom are deprived of their rights due to shortages of available schools and society's lack of awareness. NAC aspires, "to see every ASD child is cared for, parents of ASD children are supported and awareness of about ASD created in society" (Nehemiah Autism Center, 2015a). The mission of NAC is stated on their website as, "to provide care, instruction and support for children with autism and related disabilities- promoting cognitive, emotional and relational growth through individualized programs, while providing counseling and support to parents, especially mothers as they deal with these particularly challenges; teaching the parents to become active participants in their child's education and development; and finally, to raise public awareness of the nature and prevalence of Autistic Spectrum Disorder."

The goal of NAC is to, "to create an environment for children affected by Autism where they can enjoy their basic rights and Privileges and develop to their full potential (Nehemiah Autism Center, 2015b)."

Participants

24 and 38 survey questionnaires were distributed to staff members and caregivers respectively. Fourteen survey questionnaires were completed and returned from staff members (58.3% response rate) and caregivers (36.8% response rate) respectively. A total of 28 participants were included in this study; 14 staff members and 14 caregivers. Among staff members 2 were asked to participate in the semi-structured interview, both agreed to participate (100% response rate).

Staff characteristics

Among the 14 staff members that participated, 12 were female and 2 male. Ten (n=14) of participants reported to be teachers and 4 (n=14) working in administration. The staff members had range of working experience at NAC. The average experience working at NAC time was 13 months; 2 months was the minimal working experience and maximum at 45 months. A range of education level was also reported. Eight (n=14) of participants completed a university course, 3 (n=14) bachelor degree, 3 (n=14) high school, and 1 (n=14) elementary school. Three (n=14) reported to have had experience in special education previously, however did not specify. A total of 9 (n=14) of staff members reported to have no previous experience with special needs education.

Caregiver characteristics

Among the 14 caregivers that participated, 4 were female (n=14) and 10 male (n=14). On average the caregivers have enrolled their children at NAC for 7 months; 7 months at minimum and maximum 48 months.

Procedure

Sampling

Survey questionnaire

Inclusions criteria follows; staff and caregivers with a minimum age of 18 at NAC. Convenience sampling was used to collect participants to meet the inclusion criteria. This sampling method was chosen because it was the simplest, most economical, and time efficient approach to collect participants for this study (Kristensson, 2014).

Interview

Inclusion criteria follows; staff with a minimum age of 18 at NAC with sufficient level of English comprehension. Convenience sampling was used to collect participants due to time constraints as well as it was the most simplest and economical approach to collect participants to this study (Kristensson, 2014).

Data collection

Quantitative collection Survey Questionnaires

From *The Collection of Client Information*, two survey questionnaires were designed, one for staff and caregivers respectively. Questions were formatted by the author using PEOP-model (Baum & Christiansen, 2005b) and was inspired by a previous needs assessment in a school-setting (McFadden, 2010). The PEOP-model was used to help the author to map out the current occupational therapy needs of the organization and their participation in achieving their goal (Baum & Christiansen, 2005b). Furthermore to identify the environmental enablers and barriers of participating in tasks, activities, and roles which are needed to attain the goal of the organization.

A questionnaire could be completed quickly and efficiently with minimal disruption to class time. The program manager expressed that caregivers are tired in participating in studies. In consideration of these two aspects, designing a questionnaire requiring minimal time and effort to complete was most appropriate for this setting.

Staff and caregiver questionnaires consisted of 13 and 9 questions respectively (Appendix B & Appendix C). It took approximately 15-20 minutes to complete the questionnaire. Response formats included multiple choice and rank-order responses. Due to the lack of awareness of the diverse role of occupational therapy, the author felt it was most important to provide multiple-choice in the questionnaire. Majority of questions provided the opportunity for the respondent to add any information they felt was important to be included. The questions in the survey questionnaire addressed the children's occupational performance issues, what aspects of the environment the respondents found to be supportive or a barrier to achieving NAC's goal, and identified what areas an occupational therapist could contribute with. Prior the distribution, the survey questionnaires was reviewed by a staff member for clarity and readability as well as ensuring the accuracy of the translation.

The survey pack consisted of an information letter (Appendix D), consent form (Appendix E), and the appropriate version of the questionnaire (Appenix B or Appendix C).

Staff members were given a survey pack and were asked to complete the questionnaire if they wished to participate in the study. The author asked the staff members to return the packet within a week. The survey pack was sent in the students' backpacks home. The author asked the teachers to write in the communication booklet regarding the survey pack to the caregivers

Interpreter

The official language in Ethiopia is Amharic (Ethiopia Tourism Organization, 2015). An interpreter was needed to translate the survey questionnaires into Amharic and to translate the

answers back into English. The interpreter was interviewed and had to meet the following inclusion criteria: at least 1-year experience and no previous relation or connections with NAC. The interpreter chosen had 10 years experience as a translator. Currently works as a translator for his synagogue and previously has had experience translating in a clinical context.

Interview Guide

From the results of the survey questionnaires a semi-structural interview guide was developed (Appendix F). By using individual semi-structured interviews, internal information was obtained to describe in-depth the support and barriers of the environment to achieve the goal at NAC (Gupta et al., 2007). Individual interviews were chosen over group interviews which allowed the participants to discuss more openly without having to disclose their identity (Doll, 2010). The interview consisted of 7 open-ended questions and 1 "last comment" question. The questions included followed-up questions to clarify the supporters and barriers in achieving NAC's goal.

Pilot interview

The first interview served as a pilot interview. This was to ensure that the questions were understandable by the participants and that the questions addressed the aim of the study. This interview was satisfactory in achieving the aim of the study and therefore was included in the data analysis.

Interview session

The interview was conducted in a private room to minimize disturbance and ensure the content of the interview remained safeguarded. The interview was recorded with a mobile phone to save the content of the interview. Each interview was coded.

Before the interview an oral presentation regarding the content and rationale of the interview was disclosed to the participant. The participants signed a consent form to participate in the study and consented orally to participate in the interview. The interview sessions were 20-30 minutes long.

Transcription

When the interview was completed the data was transcribed into written text of the exact words said by the participants including pauses and emotional content. The author hired a transcriber to transcribe the interviews due to time constraints.

Data Analysis

Survey questionnaire

Reponses were collected and coded into an excel spreadsheet for the purpose of the data analysis. The data collected was analyzed using Microsoft Excel (2007).

Semi-structured interviews

The participants' identify has been coded to maintain confidentiality. Manifest content data analysis was applied to capture a deeper understanding of the environmental enablers and barrier influencing the goal at NAC. This approach allowed the author to categorize the common codes (Royse et al., 2009).

For each interview the qualitative data from the transcribed text has been processed in the following procedure; any pauses or repeated meaning was removed from the transcription and condensed into a meaning unit (Royse et al., 2009), thereafter the condensed meaning units were coded, these codes were analyzed into categories to describe the environmental enablers

and barriers in achieving the goal of NAC. A matrix was used to organize the data (Appendix G).

Ethical Considerations

Ethical approval was given by the supervisor of this study at the School of Health Sciences-Jönköping University in Sweden (Appendix H). NAC has given the author their permission to conduct MFS (Appenedix A).

The interpreter and transcriber together with the author read two chapters regarding confidentiality and consent from WHO's Research Ethics Committees (World Health Organization, 2009). Prior commencing the job position the interpreter and transcriber signed a contract, which made an agreement that he had read and understood the given information regarding the participant's confidentiality (Appendix H). The interpreter and transcriber chosen has no previous relation to NAC, this is to secure the participant's confidentially as well as avoiding interpreter bias.

An information letter was given to participants (Appendix D). The letter informed the participants the content of the study, and their rights. The participants were informed to keep the information letter as it provided contact details to the author. Participants were also given a consent form, which they were asked to sign prior participating in the study (Appendix E). The information letter and consent form was translated into Amharic.

The questionnaire was marked with a random alphabetic letter or number and the information letter was marked with the same symbol. The random alphabetic letter or number was to make the participants unidentifiable to the author. This ensured their confidentiality. If the participants chose to withdraw from the study they were asked to inform the author their alphabetic letter or number, making it possible for the author to remove the data connected to the participant.

When assessing needs of an organization ethical issues may be involved (Royse et al., 2009). Participants may get an expectation that the needs addressed will be met immediately after partaking the study. Therefore the author has informed participants the purpose of the study to avoid the risk of false notion.

Results

The quantitative results were presented first and organized into 3 sections that corresponded with the nature of the questions of the survey questionnaires these include occupational performance issues, enablers and barriers of the environment, and identified areas of occupational therapy participation. The quantitative results was presented in absolute numbers due to the small sample size (n= 28) (Ejlertsson, 2012). It is strongly recommended to use absolute numbers to present the results if the sample size is less than 50. Using relative numbers, would potentially give a falsified presentation of the results.

In the second section of the results, enablers and barriers of the environment, the qualitative results are presented together with the quantitative results. The qualitative data analysis resulted in 9 categories, which hold a total of 28 codes. See the Table 1 below for the distribution of the categories and codes. The aim was to describe more in-depth the barriers and enablers of achieving NAC's goal. Each interview has been coded into a number (1, 2) and a letter (A, B).

Categories	Codes
Training based on evidence enhances quality of services provided	3
Knowledge of staff members enhances quality of services.	3
Need for training opportunities for the caregivers.	2
Importance of communication between caregivers and staff.	4
Co-worker relationship is valued.	3
Government policies dictates the child's development.	4
Stigma hinders the organization from achieving the goal.	6
Religion	2
Cultures of Addis Ababa may hinder the care of children with ASD.	1
Total number of codes :	28

Occupational performance issues

Twenty-five occupational performance issues were provided for the staff members and caregivers to identify. See Appendix I for table 2, which presents the frequency of reported the occupational performance issues for the children in absolute numbers. For staff, the most frequently reported occupational performance issues was behavior management at 12 reports (n=14), following instructions 12 reports, and social skills 11 reports. For caregivers (n=14) the most frequently reported areas was engagement in play at 10 reports, dressing independently 10 reports, social skills 9 reports, emotional behavior 9 reports, and communication 9 reports.

When participants were asked to rank the most challenging occupational performance issue 1-5, one being the most challenging and five being the fifth most challenging, staff members ranked behavior management at 3 reports (n=14), social skills 3 reports, communication 3 reports, cleaning up after self 3 reports as the most challenging occupational performance issue. Caregivers reported behavior management and communication at 10 reports (n=14) to be the most challenging areas for their child. See Appendix J for table 3 which presents the ranking frequency of staff and caregivers.

Enablers and barriers of the environment

Survey questionnaire results

Various environmental factors were provided in the survey questionnaire to identify the supportive and unsupportive factors in achieving the goal at NAC, as well identifying what factors staff and caregivers find supportive to themselves. See Appendix K for table 4, 5, 6, & 7, which presents the frequency in absolute numbers of staff members and caregivers whom report the environmental factors that they find to be supportive and unsupportive in achieving NAC goal.

Staff members reported training opportunities at 11 reports (n=14), parent relationship 10 reports, and school material 10 reports to be the most supportive. Caregivers reported training opportunities at 14 reports (n=14), parent relationship 10 reports, time management 8 reports, and government policies 8 reports to be the most supportive.

Regarding the most supportive factors to achieve the goal of NAC, staff members reported staff relationship and administration at 8 reports (n=14) to be the most supportive factors. Caregivers reported school material at 11 reports, training opportunities 10 reports, parent relationship 10 reports, and government policies at 10 reports to be supportive of NAC's goal.

Regarding the most unsupportive factors to achieve the goal of NAC, staff members reported stigma at 4 reports (n=14), Ethiopian culture 3 reports (n=14), and religion 3 reports (n=14). Caregivers reported stigma at 10 reports (n=14), Ethiopian culture 5 reports (n=14), government policies 4 reports, and religion 4 reports (n=14) to be the most unsupportive factors to achieve NAC's goal.

Semi-structured interview results

Enablers

Training based on evidence enhances quality of services provided

Participants expressed that training opportunities based on the latest research provide the staff members with support to improve their teaching style. It also gives them more confidence to brainstorm ideas of their own related to the training opportunities the aim to improve the quality of services provided to the children. It has been reported by staff members that they are in need for training opportunities that are based on the latest research due to the unpredictable nature of ASD. By receiving training based on recent evidence helps the organization to provide good quality services to met the goal of NAC.

"..recent research help us to get recent information about the disorder.." (1:A)

Knowledge of staff members enhances quality of services

A participant reported that training opportunities allow the staff members to understand underlying factors of a problem, which helps them to provide better quality service to support the child to become more capable in society. It was also reported that the knowledge regarding how to use school materials with the aim of developing skills was important to have

"The children to be more develop their skills, social skills, life skills and if uouif you give staff training opportunities they know about the problem and they know about the how to solve the problem and set them to make the children to be cable in the society." (2:B)

Importance of communication between caregivers and staff

Participants expressed of importance of communication between staff members and caregivers. Once a month the staff and caregivers meet to discuss what the children have achieved and what areas they need help with. A participant disclosed that some caregivers are not involved in their child's learning and highlights the need to motivate caregivers to become active participators in their child's education. It was also reported that many caregivers are not confident with helping their child's learning. The teachers expressed to the participants it was important to know how the child behaves at home. It was stressed that a good communication is needed to assist the child to develop his/her skills at the organization and at home.

"We do not see how the children act in their home, how they behavior and how they communicate with their parents, sister or brothers. It's more important to communicate with parents." (2:B)

"...one student are learning in this place and he must apply in his homes also. Parent relationship is important for the consistency of learning for the students. " (1:A)

Co-worker relationship is valued.

Having a good co-worker relationship is important in achieving the goal of NAC. Each teacher has different capacities for different skills therefore it is important for teachers to

communicate and help each other with areas they struggle in. For areas that all teachers find difficulty in they feel comfortable enough to brainstorm ideas and possibilities with each other. If a problem arises the teachers and administration feel that they can discuss freely to each other how to solve the problem. A participant disclosed that the progress of the children is discussed between teachers and administration. A good relationship has been reported to provide the children with appropriate and relevant training.

"If there is a relationship between the staff member and the administration of the one student gets appropriate training for them." (1:A)

"We can talk to each other we try come up with new ideas, new possibilities so it is helping the children to achieve their goals." (2:B)

"... you are one are filling the cup of anothers." (1:A)

Need for training opportunities for the caregivers

Caregivers have a role in the provision of their child's development and teaching must be consistent according to participants. It was highlighted that there is a need to provide counseling and training for the caregivers. Many caregivers asked teachers how they teach their children and why they cannot come to their homes to teach. A participant reported that training opportunities are needed to address caregivers how they can actively participate in their child's education in the home setting.

"Many parents mention they need counseling and training from us" (1:A)

"We need more training opportunities because can uses their own home when the children stay at home" (2:B)

Barriers

Government policies dictate the child's development

Both participants reported the government was supportive. It was reported that policies should strictly apply to children with ASD. According to participants the government is not aware of children with ASD and there are no policies or written document upon the matter. If a policy is adapted children with ASD may be integrated into a normal class. Currently only wealthy families enroll their children with ASD into a normal class. For families that are financially restricted this is not possible. The government should be made aware on this issue to provide a good environment for children with ASD and further to encourage child development. If no action is taken place the development of the child is limited.

"Government policy is strictly applied to thems." (1:A)

"In our government policy they don't have any structural things about autism." (2:B)

Stigma hinders the organization from achieving the goal.

Ethiopia is a spiritual society where when people are faced with a problem they believe it is a punishment from God for their sins. Caregivers have expressed this matter to staff in regards to this. Not only caregivers themselves, but the people in their communities judge them for the sin they accuse them for committing. Some caregivers hide their children from the community because of the fear of being isolated from the community and denied to participate in societal activities. Awareness of ASD are lacking among communities of Addis Ababa. This lack of awareness leads to stigmatization towards children with ASD and their

families. Members of the community do not understand the implications of ASD. When stigma is present unsupportive attitudes towards children with ASD and their families influence the achievement of NAC's goal.

"The Ethiopian society is a spiritual society and if any problem they face they assume that this is fro God. They assume that they are cursed with this thing. God punished them. Most parents assume they maybe sinned in some way." (2:B)

Religion

A participant shared that religion is not only an unsupportive factor for NAC, but also other centers as well. At NAC they only support those who practice similar religions. Equal opportunities do not exist with people of different religious backgrounds. The goal is not related to religion. If NAC continues to work in this way it does not provide a good environment to achieve the goal.

"...if we are only supporting those who have similar religions, we are not supporting anothers..." (1:A)

A participant reported that more caregivers disclosed to him that religion is a supportive factor. A few of them have gone to church for the priest to pray for their child to get healed, and has shown positive results.

Culture diversity may hinder the care of children with ASD

There are many different ethnic groups living in Addis Ababa. A participant reported that one ethnic group believes that they are above other ethnic groups. The ethnic groups discriminate one another. There are no studies present regarding children with ASD living in different cultural groups. The origin of ethnic group may have implications on the care of children with ASD.

".... you are entering to the discriminations one. You are saying one nations are above anothers." (1:A)

Identified areas that an occupational therapist can contribute

Twenty-six skills of what an occupational therapy could potentially assist with was provided. See Appendix L for table 8, which presents the frequency of reports in absolute numbers of what areas occupational therapists can contribute to. For staff, the most frequently reported area was leisure and play at 12 reports (n=14); the least frequently reported areas were meal preparation, sensory management, and memory 3 reports. For caregivers (n=14) the most frequently reported area was communication and social skills at 12 reports; the least frequently reported area was other at 3 reports. Participants did not indicate what skill an occupational therapist can help with, when they selected other unfortunately.

When participants were asked to rank the importance 1-5 of the areas that occupational therapists can contribute to, one being the most important and 5 being the fifth most important area, staff members ranked stress management to be most important at 3 reports (n=14); thereafter stress management 3 reports and learning 3 reports; cognitive skills 3 reports and handwriting 3 reports; making friends 3 reports; and cognitive skills 3 reports as the fifth most important area. Caregivers ranked behavior management being most important at 4 reports (n=14), thereafter social skills 3 reports; following routines, communication skills, learning, and cognitive skills at 2 reports; attention 4 reports; and attention 4 reports as the fifth most important area. See Appendix M for table 9, which presents the ranking frequency of staff and caregivers.

Discussion

Method

Pre-understanding

In order to objectively measure a person's experiences and thoughts the researcher must reflect upon his/her pre-understanding before commencing a study (Kristensson, 2014). The researcher must be made aware of the implications of how one's pre-understanding may influence the process and results of the study. Granskär and Höglund-Neilsen (2008) empathize that in qualitative research pre-understanding is vital to reflect upon in order to achieve and apply analysis on the obtained data, this will increase the credibility of the study.

The author is an occupational therapy student at the School of Health Sciences at Jönköping University. Completed a total of 2.5 years of the Occupational Therapy program: three semesters in Sweden and 2 semesters at Deakin University in Australia. The author has only been exposed to western education, and has not have any experience with the Ethiopian or African culture. The author has also never travelled to a developing country previously. In preparation for conducting this study the author attended Healthcare in Developing Countries course at Jönköping University and 3-day MFS course provided by SIDA.

Participating in a service-learning project for 12 weeks provided the author with the opportunity to familiarize with the cultural context and current services provided by the organization. This helped the author to design appropriate survey questionnaires and semi-structured interview guide that suited the context, which increases the credibility of the study (Shenton, 2004).

The author acknowledges that the results can be influence by one's western perception of Ethiopian or African culture. It is therefore important to maintain objective questions that will not influence the participants to answer in a particular matter.

Study design

The choice of study design was most appropriate as Doll (2010) highlights the importance of adopting mixed-methods design to construct a needs assessment that captures a comprehensive picture of the expressed needs. When using mixed-method design the main advantage is that the limitation of one method is compensated by the other method's strength (Creswell, 2015). Triangulation has been used as two methods are integrated with one another to address the same aim (Westat, 2002). This strengthens the validity of the results as it provides the author with a comprehensive perspective of the results. In two interview questions the author received contradictory information compared to the findings of the related questions in the survey questionnaire. This is one problem of triangulation that may occur, and unfortunately cannot be resolved. This questions the trustworthiness of the study to an extent.

Participants

The sample size was much smaller than the author anticipated. Only 14 out of 24 staff members completed and returned the survey questionnaire and only 14 out of 38 staff members completed and returned the survey questionnaire. It was previously reported by the administration that caregivers were tired in participating studies; this may be an explanation to the low response rate. Also the author has been made aware that some caregivers are illiterate, which may explain the low response rate. The author asked the staff members to put one survey packet in each student's backpack and to inform caregivers in the communication booklet the purpose of survey questionnaire. The author did not witness whether this task was completed or not. There is a risk that some staff members did not place the survey packet in

the backpack of the student and therefore the survey questionnaire was never given to the caregivers. This could have also explained the low response rate of the caregivers. Unfortunately having a low sample size decreases the validity of the statistical results.

The interviews took place at the organization; there is a risk that the participants were told to participate in the study or that they felt like they had to participate. The author did convey to the director that participation of the study was completely voluntary. This may have influenced the result by the participants uncomfortable to disclose his/her honest opinions. This decreases the credibility.

Convenience sampling was used to due to it was the simplest, most economical, and time efficient approach to collect the participants (Kristensson, 2014). This sampling method may have impacted the results, as the participants collected may not be representative of the population, making it hard to generalize the results to another context. There was an equal representation of staff members (n=14) and caregivers (n=14). This may have increased the credibility as the equal amounts of data collected from staff members and caregivers. However only two staff members were asked to participate in the interview and the author did not ask caregivers. There is no representation of caregivers for the interviews. This decreases the credibility of the study. When looking at the gender distribution there were more females representing staff members and for caregivers males represented more. This could have influenced the result, as there is an uneven distribution of female and males.

Setting

Nehemiah Autism Center is one of two centers of all Ethiopia attending to children with ASD, making it hard to transfer the results to rest of Ethiopia. There is another organization in Addis Ababa however, attending to the same population as Nehemiah Autism Center is. The results of this study may be transferability for that organizational context to an extent.

During the time of data collection the elections in Ethiopia was coming up on May 20th. The author experienced that this was a sensitive time for the Ethiopians. Many locals were unwillingly to share their honest opinions in fear of it being misinterpreted by the government. This is a factor, which could possibly influence the results. The questionnaire indicated that the government was a supportive factor. The content of the interviews never claimed the government to be unsupportive, but did disclose information to suggest that the government wasn't supportive enough to achieve the goal of the organization. In consideration to this aspect, the credibility of the study may have decreased.

Ouantitative Data collection

An interpreter was used to translate the survey questionnaire, information letter and the consent form. The interpreter had 10 years of experience and no previous relation with NAC. The interpreter had to met an inclusion criterion, which included previous experience and no relation to NAC. This was to avoid interpreter bias. Also having an interpreter with previous experience may have increased the credibility of the content of the translated items, this could have been positive for the results.

A staff member with previous experience of translating to and from English and Amharic reviewed the survey questionnaire, information letter, and consent form. The staff member checked the accuracy of the translation. The clarity and readability was also reviewed. The staff member reported that the translation was accurate and the content was understandable. The content of the translated material was validated increasing the credibility.

The author did not have a caregiver check the survey questionnaire for clarity and readability. Some terms may have been difficult to understand and this could potentially decrease the creditability of the study. One caregiver noted on the questionnaire that they did not understand some of the terminologies and questions. A relative to a caregiver wrote that he/she helped the caregiver to complete the survey questionnaire because the caregiver could not read. Perhaps it would have been more appropriate for the student to complete the survey questionnaire orally with the participants and a translator present. This is something to take consideration to in future studies.

Qualitative Data collection

The primary language in Ethiopia is Amharic (Ethiopia Tourism Organization, 2015). The author interviewed the participants in English, which is not their native language. This could of decreased the credibility of the results as the participants may have felt it was difficult to explain in-depth their experiences and opinions.

The author followed a semi-structured interview guide containing open-ended questions, which allowed the author more control during the interviewing session while addressing the aim (Trost, 2010). Using open-ended questions provided an opportunity for the participants to disclose freely their experiences and opinions (Patton, 2002).

The interview started with a proper introduction about content of the interview and its purpose. Patton (2002) stresses that a proper introduction helps the interviewee to respond indepth to the questions and that the interview itself adopts a natural flow.

The interview session took place in a separate room at NAC to increase the participants' willingness to disclose his/her experiences and opinions. The reasoning was to increase the credibility of the study as well as safeguard the content of the interview. Unfortunately this separate room had cupboards where materials were stored and during an interview someone disturbed the session to retrieve materials from the cupboard. This may have influenced credibility of the results.

Do to time constraints the author hired a transcriber. The transcriber was informed to write every word that was spoken during the interview, also to include pauses. The author listened through the audio file with the transcription to ensure that nothing was left out; this was to increase the credibility of the results (Trost, 2010).

Manifest content analysis was adapted to analysis the content of the interviews. Only the author analyzed the data, this may of affected the results negatively. The author originally planned to use member checking to check the accuracy of the interpretation of the interview with the participants. This would have increased the credibility of the study.

Result Discussion

This section will address the content of the results and its connection to the aim and link previous studies when appropriate. There is limited amount of research regarding the topic of this study (Newton & Chugani, 2013).

Occupational performance issues

The reported occupational therapy issues of the children at NAC were similar to cases in developed countries (American Occupational Therapy Association, 2008; Ashburner et al., 2014). Communication was an occupational performance issue reported frequently by staff members and caregivers. Mankoski et al (2006) reported that most cases of ASD in Africa are non-verbal.

Enablers and barriers of the environment

When conducting a needs assessment the evaluator must take in consideration what aspects of the organization's environment enable and act as barriers to participate in necessary and desired occupations (Timmreck, 2003). This helps the evaluator to determine existing resources that should be utilized by the organization to achieve the goal. From the results it was highlighted that the biggest support of the organization was co-worker relationship this is one important factor that should be utilized.

Identified areas of that an occupational therapy can contribute to

No previous occupational therapy needs assessment has been conducted in Sub-Saharan Africa.

Role of Occupational Therapy

The results indicated that there is a role of occupational therapy for an organization attending to children with ASD in Addis Ababa, Ethiopia. There are many needs that an occupational therapist can address.

Occupational therapy is a new emerging profession in Ethiopia. Staff members and caregivers may be unaware of the role of occupational therapy for children with ASD. It is the duty of an occupational therapist to advocate the potential of occupation therapy services and how it can meet the areas of identified needs to assist childhood development and therefore achieve the goal of NAC. The results of this study support the advocacy of occupational therapy participation.

When implementing services to met the identified needs, it is important to include members of the organization in the process. Especially when explaining how the needs of children with ASD fit into the domain of occupational therapy. Furthermore explain how a therapist can support the development of skills to

Further research

From the literature reviewed regarding ASD in Africa it is prominent that there is significant lack of research to describe the current situation in terms of prevalence, etiology, characteristic, and management of ASD (Bakare & Munir, 2011). Policy makers of Africa must be made aware of child and adolescent mental health service provision otherwise this will impact the population's childhood development negatively resulting a decrease of economic growth for the country (Cockburn & Kabubo-Mariara, 2010). Further research upon the topic of ASD in Africa is needed to highlight the need for mental health services provision.

Another area needed for investigation is the experiences of children with ASD and their caregivers. Lygnegård et al. (2015) systematically reviewed the generic and special needs of children with disabilities living in poverty settings in low and middle-income countries. Only one out of 11 articles was from a child's perspective. It has been stressed that the understanding of child health is incomplete without researching the child's perspective (Irwin & Johnson, 2005). Therefore it would be a huge area of interest to investigate the child's perspective regarding their disability in low and middle-income countries.

Further research regarding the role of occupational therapy in Africa would supply relevant insights and assists the development of occupational therapy, promote development of training centers meeting the WFOT Minimum Standards, support the existing occupational

training centers, and encourage African countries to become members of WFOT (Occupational Therapy Africa Regional Group, 2015; Therapists, 2008; World Federation Occupational Therapists, 2008)

Conclusion

In conclusion the organization of Nehemiah Autism Center in Addis Ababa reported a great need for occupational therapy. All skills were selected as an area of interest for occupational therapy participation. Having the participants rank the importance of each skill may help future therapists and/or occupational therapy students to construct a client-centered intervention and/or project. It also allows the organization themselves to become aware of the service users prioritized areas of needs. By identifying aspects that are supportive and unsupportive this provides the organization with the information of what resources should be continued to be utilized, and what barriers need to be addressed.

Implications and recommendations

Implications and recommendations to achieve the goal of NAC is considered to be as follows;

- Encourage establishment of government policies concerning mental health provision. Policy makers of sub-Sahara Africa must be made aware of child and adolescent mental health service provision otherwise this will have a great consequence of the population's childhood development.
- Greater opportunities for training for staff members and caregivers addressing the latest research regarding ASD.

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To Whom It May Concern:

Please allow this to serve as an invitation letter confirming that the following Occupational therapy student is welcome to do her Minor Field Study (MFS) and practical placement at the Nehemiah Autism Center, Megenagna, Addis Ababa, Ethiopia February 2015-June 2015:

Silje Hammarlund 920709-0540

Please feel free to contact me if you have any further questions.

Rahel Abayneh

Thank you!

Director

Appendix B Survey- staff members

Please read each questions carefully and answer honestly. If you find a question to be uncomfortable to answer you may skip it. Please tick boxes that apply and fill in the spaces if needed.

1.	Indicate your gender.	
	Female	
2.	What is your job title at Nehemiah Autism Center?	
3.	How long have you worked at Nehemiah Autism Center?	
	Years	
	Months	
4.	Please indicate your level of education and state the area of study yo completed.	ou've
	Elementary School	
	High School	
	University course(s)	
	Bachelor Degree	
	Master Degree	
	Currently studying	
	Other	

5.	. Have you had any training in special education?				
	No \square				
	Yes				
	If yes, please specify the training belov	<i>V.</i>			
6.	6. What previous experience have yo Nehemiah Autism Center?	u had that has prepared you to work at			
	University Degree				
	Placement				
	Internship \Box				
	Volunteer \Box				
	Previous employment \square				
	None				
	Other \square				
	Other				
7.	7. In general, what areas do the child that apply.	ren have difficulty in? Please tick the boxes			
	☐ Behavior management ☐	Completing tasks			
	☐ Social skills ☐	Following instructions			
	\square Emotional behavior	Multitasking			
	☐ Stress management ☐	Making Friends			
	☐ Communication ☐	Follow routines			

	☐ Dressing indepen	dently	\Box Toiletin	g independently	
	☐ Feeding independ	lently	Engage	ment in classroom activities	
	☐ Engagement in pl	ay	Memory	I	
	☐ Upper limb motor	skills	☐ Meal pr	eparation	
	☐ Academic skill adv	vancement	Problem	solving	
	☐ Cleaning up after s	self	☐ Hand w	riting	
	Sensory manageme	ent			
	Other		\Box Other		
	□ Other		\Box Other		
8.	greatest challenges 4, 5. The greatest cl	for the stud	ents. Rank	n 5 areas that you believe are these areas with the numbers 1 and the least challenging ra	s 1, 2, 3,
	(1)				
	(2)				
	(3)				
	(4)				
	(5)				
9.	What factors have y	you found to	be support	tive?	
	☐ Time managemen	nt 🗆 Parent re	lationship	☐ Physical Environment	
	Resources	Finances		☐ Government policies	
	Staff relationship	☐ School M	I aterial	☐ Training opportunities	
	Administration	Managen	nent style	Other	
	□ Other	List of	Other_	PFE.COM	

10. What aspects of the environment support the goal at Nehemiah Autism Service? The goal states as, "to create an environment for children affected by Autism where they can enjoy their basic rights and privileges and develop to their full potential."					
Management	☐ Parent rela	tionship	☐ Built Environment		
Resources	Finances		☐ Government policies		
☐ Staff relationship	☐ School Ma	terial	☐ Training opportunities		
Administration	☐Ethiopian (Culture	Religion		
Stigma	Other		_ Other		
11. What aspects of the Service?	e environment	t do not su	pport the goal at Nehemiah Autism		
Management	☐ Parent rela	tionship	☐ Built Environment		
Resources	Finances		☐ Government policies		
☐ Staff relationship	☐ School Ma	terial	☐ Training opportunities		
Administration	☐ Ethiopian (Culture	Religion		
Stigma	Other		_ Other		
-	ck the boxes tl	hat you ide	with the following skills. From the entify as areas, if any, you feel that		
Behavior manage		Leisure :	·		
☐ Stress manageme	ent	∐Learning □			
☐ Multitasking ☐ - · · · ·		∐Memory □ -			
☐ Cognitive skills		☐ Communication skills			
☐ Toilet manageme	ent	∐Attentio	n		

☐ Feeding independently	☐ Social skills
\square Dressing independently	\square Making friends
\square Following instructions	\square Following routines
\square Completing school tasks	☐ Social skills
☐ Meal preparation	\square Engagement in classroom activities
☐ Upper limb motor skills	☐ Cleaning up after self
☐ Hand writing	Academic skill advancement
☐ Sensory management	☐ Problem solving
□ Other	□ Other
□ Other	
Other 13.From the question above please most important. Rank these are	e write down 5 areas that you believe are the eas with the numbers 1, 2, 3, 4, 5. The most 5 being the fifth most important area.
Other 13.From the question above please most important. Rank these are	eas with the numbers 1, 2, 3, 4, 5. The most
Other 13. From the question above please most important. Rank these are important area ranked 1, and 5	eas with the numbers 1, 2, 3, 4, 5. The most
Other 13. From the question above please most important. Rank these are important area ranked 1, and 5	eas with the numbers 1, 2, 3, 4, 5. The most
Other 13. From the question above please most important. Rank these are important area ranked 1, and 5 (1)	eas with the numbers 1, 2, 3, 4, 5. The most
Other 13. From the question above please most important. Rank these are important area ranked 1, and 5 (1) (2) (3)	eas with the numbers 1, 2, 3, 4, 5. The most

Final comments:

Thank you for participating!

Appendix C Survey- primary caregivers

Please read each questions carefully and answer honestly. If you find a question to be uncomfortable to answer you may skip it. Please tick boxes that apply and fill in the spaces if needed.

1.	Indicate your gender.	
	Female Male	
2.	How long has your child been a	t Nehemiah Autism Center?
	Years	
	Months	
3.	What areas does your children apply.	have difficulty in? Please tick the boxes that
	☐ Behavior management	☐ Completing tasks
	☐ Social skills	☐ Following instructions
	☐ Emotional behavior	□Multitasking
	☐ Stress management	☐ Making Friends
	☐ Communication	☐ Follow routines
	☐ Dressing independently	☐ Toileting independently
	☐ Feeding independently	☐ Engagement in classroom activities
	☐ Engagement in play	Memory
	☐ Upper limb motor skills	☐ Meal preparation
	Academic skill advancement	☐ Problem solving
	☐ Cleaning up after self	☐ Hand writing
	Sensory management	
	□ Other	□ Other
	Other	\square Other

4.	From the question above please write down 5 areas that you believe are the greatest challenges for your child. Rank these areas with the numbers 1, 2, 3, 4 5. The greatest challenging area ranked 1 and the least challenging ranked 5.			
	(1)			
	(2)			
	(3)			
	(4)			
	(5)			
5.	What factors have y	ou found to be support	cive in providing care for your child?	
	☐ Time managemen	at Parent relationship	☐ Built Environment	
	Resources	Finances	☐ Government policies	
	Staff relationship	☐ Training opportunitie	s Administration	
	☐ Other		Other	
6.	Service? The goal s	tates as, "to create an er	the goal at Nehemiah Autism vironment for children affected by ts and privileges and develop to their	
	Management	Parent relationship	☐ Physical Environment	
	Resources	Finances	Government policies	
	Staff relationship	School Material	☐ Training opportunities	
	Administration	☐ Ethiopian Culture	Religion	
	Stigma			

	Other			□ Other	
7.	What aspects of the Service?	environme	ent do not si	ipport the goal at Nehemiah Au	tism
	Management	Parent re	elationship	☐ Physical Environment	
	Resources	Finance	S	☐ Government policies	
	☐ Staff relationship	☐ School I	Material	☐ Training opportunities	
	Administration	Ethiopia	n Culture	Religion	
	Stigma				
	□ Other			□ Other	
•	0 1.1				
8.		ck the boxes	s that you id	e with the following skills. From lentify as areas, if any, you feel t	
	Behavior manage		Leisure	and Play	
	☐ Stress manageme	nt	Learnir	ng	
	Multitasking		□Memor	у	
	☐ Cognitive skills		☐ Commu	inication skills	
	☐ Toilet manageme	nt	Attenti	on	
	☐ Feeding independ	lently	☐ Social s	kills	
	☐ Dressing indepen	dently	Making	friends	
	☐ Following instruc	tions	Followi	ng routines	
	☐ Completing school	ol tasks	☐ Social s	kills	
	☐ Meal preparation		□Engage	ment in classroom activities	
	☐ Upper limb motor	skills	Cleanin	g up after self	
	☐ Hand writing			nic skill advancement	
	Sensory managem	ent	Probler	n solving	

	☐ Other	□ Other
	□ Other	
9.	most important. Rank these are	e write down 5 areas that you believe are the eas with the numbers 1, 2, 3, 4, 5. The most being the fifth most important area.
	(1)	
	(2)	
	(3)	
	(4)	
	(5)	
	Final comments:	

Appendix D

Information Letter regarding participating in the study

Background & aim of the study

I would like to formally invite you to participate in a study designed by a student from Jönköping University in Sweden. The aim is to conduct a needs assessment to identify the occupational therapy needs at Nehemiah Autism Center.

Permission of participation

This study is interested in gathering information from staff members and caregivers. Therefore you are being asked to participate in the study. Before participating you'll be asked to give your consent.

What is the procedure of the study?

I will distribute a survey that will take approximately 10 minutes to complete.

What are the advantages?

Hopefully the needs assessment will provide relevant insights in order to set up achievable and relevant goals and further enhance health and well-being.

Future occupational therapists and students may access the thesis to set-up appropriate interventions that suits the needs identified.

Confidentiality

The information collected from the interview will be kept and dealt with confidentiality.

Your identity and the information gathered from you will be dealt with confidentiality. This means that no one will access your information except for the student and her supervisor.

An interpreter will be used to translate the content of the survey. The interpreter has been made aware of the confidentially. The interpreter has sign a document stating that he is aware and understands the confidentially of the study. The interpreter chosen will have no previous relation or connections with the Nehemiah Autism Center. This is to secure your confidentially.

Access the results of the study

The results will be presented to those who are interested. A printed copy of the Bachelor thesis will be sent to the Nehemiah Autism Center for staff and caregivers. A digital copy may be requested by sending the student an email.

Your rights as a participant

Participation in this study is voluntary. Meaning that you don't have to participate if you wish not to.

You have the right to withdraw from this study. This means that you can end your participation and withdraw your results in 4 weeks time. You may leave the study without providing an excuse.

Those who are responsible

The supervisor of this study is Ann Johansson, University lecturer of the Department of Rehabilitation at the Jönköping University.

If anything is unclear please contact me at, Silje Hammarlund

Occupational Therapist student at Jönköping University

 $\frac{silje.oline.hammarlund@gmail.com}{0929296701}$ E-mail:

Mobile number:

Appendix E

Consent form

I confirm the following in regards to the Information Letter concerning;

(Please tick the boxes if yo	u understood for rights, example ☑)	
I received & understand t	he information given	
I understand the content	of the study	
I choose to participate on	a voluntary basis	
I understand that I may w	rithdraw my participation at any time	
I understand that not part my role at the Nehemiah	ticipating this study will not affect Autism Center negatively	
I hereby agree to partici student, Silje Hammarlu	pate in this study conducted by Occi nd.	ıpational Therapy
Date:		
Signature:		

(Please turn in the consent form to Silje)



Appendix F

Interview guide

Oral Information

First off I'd like to thank you for participating this interview.

This interview will take approximately 30 minutes. In this interview I'll be asking you a series of questions regarding the barriers and supportive factors in achieving Nehemiah Autism Center's goal. What you say in this interview will be dealt with confidentiality. Meaning the information will not be shared with others. I would appreciate you to be honest when answering to the questions.

Before we start the interview, I will give you a piece paper stating the goal at Nehemiah Autism Center. This is to help you to answer the questions.

Questions

- 1. The top 3 items that staff members reported to be supportive are: training opportunities, school materials, and parent relationship.
 - a. Why do you believe these items were ranked as supportive?
 - b. Have the staff members mentioned anything that supports this report?
- 2. The top 3 items that parents reported to be supportive are: training opportunities, time management and government policies.
 - a. Has the parents mentioned anything to you personally or through the communication booklet that supports this report?
- 3. Stigma was reported by parents and staff members to be the most unsupportive factor of achieving Nehemiah Autism Center's goal.
 - a. Could you please explain why you believe this was ranked the highest?
 - b. Has the staff and/or staff members mentioned anything to you personally or through the communication booklet that supports this report?
- 4. Religion was reported by parents and staff members to be an unsupportive factor of achieving Nehemiah Autism Center's goal.
 - a. Could you please explain why you believe this was ranked highly?
 - b. Has the staff and/or staff members mentioned anything to you personally or through the communication booklet that supports this report?
- 5. Ethiopian culture was reported by parents and staff members to be an unsupportive factor of achieving Nehemiah Autism Center's goal.
 - a. Could you please explain why you believe this was ranked highly?
 - b. Has the staff and/or staff members mentioned anything to you personally or through the communication booklet that supports this report?
- 6. The highest ranked items according to staff members that supported Nehemiah Autism Center's goal was staff relationship and administration.
 - a. Why do you believe these items were ranked the highest?
 - b. Have the staff members said anything previously that supports this? If yes, what?

- 7. The highest ranked items according to parents that supported Nehemiah Autism Center's goal was training opportunities and government policies.
 - a. Why do you believe these items were ranked the highest?
 - b. Has the staff and/or staff members mentioned anything to you personally or through the communication booklet that supports this report?

Follow-up Questions

- 1. Can you please explain more about what you mean when you say...?
- 2. Do you have an example?
- 3. Can you please tell me more about...?

Last comment by respondent

Do you have anything you would like to add?

Last words from interviewer

Thank you for your time. If you have any concerns regarding this interview please feel free to contact me. You will be contacted the end of this week by telephone so that I can check with you that I've made the right interpretation of this interview. When the final report of this study has been completed you and the other participants will be invited to a presentation of the results. During this presentation the information from this interview will not directly identify you. I'll be discussing the overall results.

Do you have any questions at this moment?

Thank you for your time. I appreciate it.

(to be shown to interviewee)

Nehemiah Autism Center's Goal

To create an environment for children affected by Autism where they can enjoy their basic rights and privileges and develop to their full potential.

Appendix G



Project title: To investigate the current services provided at Nehemiah Ann Assessment.	ism Center	the by completin	g a Neods
Student/students: Silje Hammarlund			
Supervisor: Ann Johansson			
 Can the project involve any risks for the participant? (patient, subject, informant)? 			
a/ Medical risk b/ Pain c/ Threat to personal integrity d/ Other discomfort	Yes	Possibly	No.
2. Can it be guaranteed that the participants will not be identified in the results of the project?	E2		
 Are the participants involved in the project on their own free wi 	⊠ II?		
Can the participant, at any time and without reason, withdraw their participation?			
. Will the study include a register of participants, if yes who is	\boxtimes		
responsible for the register and to whom is the register reported:			×
(person responsible for registration)			
How is the written information presented? Is the project described in a way that the participants understand the purpose of the study. (no technical terms, plain English)			
Is it clear that the patient's treatment/care will not be influenced to choice to participate in the study or not?	y the		
Is it clear that the patient's treatment will not be influenced by the choice to withdraw from the study?	\boxtimes		

	Σ	3		Ē
7. Will the results be shared with the participants?	Σ	3		Γ
The questions above are answered correctly.				
Jönköping, date:				
2015-02-19	0	1		
Silje Hammarleond 6	lun 7	e hori	m	
Student/students Superv	risor			
선 나라 있는데 열린 그리다고 있었다.				
			The second	

Appendix H

Contract form- translator

I confirm the following in regards to World Health Organization's Research Ethics Committees concerning;

(Please tick the boxes if you understood for rights, e	xample ☑)	
I received & understand the information given		
I understand the ethical principle of confidentiality		
I understand that participants' personal information	must be safeguarded	
I understand that I may not disclose the identity of the	ne participants	
I hereby agree to obey to the ethical principles men Research Ethics Committees	tioned in World Health Org	ganization's
Date:		
Signature:		
Contact information to the student conducting this study:	silje.oline.hammarlund@g	gmail.com
Supervisor, Ann Johansson:	Ann.Johansson@hhj.hj.se	

Appendix I

Table 2 represents the frequency of reports made by staff members (n=14) and caregivers (n=14) regarding areas they identify the children have difficulty in.

Areas which the children find difficulty in	Staff Members	Caregivers
Behavior management	12	8
Social skills	11	9
Emotional Behavior	9	9
Stress management	8	4
Communication	5	9
Dressing independently	7	10
Feeding independently	10	4
Engagement in play	10	10
Upper limb motor skills	3	3
Academic skill advancement	8	7
Cleaning up after self	9	6
Sensory management	4	2
Other	0	0
Other	0	0
Completing tasks	3	7

Following instructions	12	7
Multitasking	3	5
Making friends	7	7
Follow routines	3	7
Toileting independently	9	7
Engagement in classroom activities	5	4
Memory	7	5
Meal preparation	5	7
Problem solving	6	5
Hand writing	6	7
Other	0	0
Other	0	0

Appendix J

Table 3 represents the frequency of reports made by staff members regarding the top 5 most challenging occupational performance issue. (1 = most challenging and 5 = fifth most challenging). Staff members (n=14)/caregivers (n=14).

Areas which the children find difficulty in	Rank 1, Frequency	Rank 2, Frequency	Rank 3, Frequency	Rank 4, Frequency	Rank 5, Frequency
Behavior	2/4	4 /2	4 /0	4 /0	0.40
management	3/4	1/3	1/0	1/0	0/0
Social skills	3/1	0/1	3/0	0/1	0/0
Emotional	0/1	0./0	1 /0	0/0	0/1
Behavior	0/1	0/0	1/0	0/0	0/1
Channe					
Stress	0/0	0/1	1 /0	0/0	0/1
management	0/0	0/1	1/0	0/0	0/1
Communication	3/4	3/2	0/1	0/1	2/0
Dressing					
independently	0/0	1/1	0/0	1/1	0/2
Feeding					
indepenedently	0/0	1/2	3/0	2/0	2/1
Engagment in					
play	0/1	0/1	2/2	0/0	1/2
Upper limb					
motor skills	0/0	0/0	0/1	0/1	0/0
Academic skill					
advancement	0/0	0/0	0/2	1/0	2/0
Cleaning up					_, _
after self	3/0	0/2	0/0	1/1	1/0
	,	,	,	,	,
Sensory					
management	0/0	0/0	1/0	2/0	0/0
Other	0/0	0/0	0/0	0/0	0/0
Other	0/0	0/0	0/0	0/0	0/0
Completing	,	<u>, </u>	•	,	
tasks	0/0	0/0	0/1	0/0	0/0
Following	-		-	-	-
instructions	0/0	3/0	0/1	0/1	2/0

Multitasking	0/0	0/0	0/0	0/0	0/0
Making friends	0/0	0/0	1/1	0/4	2/0
Follow routines	0/0	1/0	0/1	0/0	0/1
Tailatina					
Toileting	2/2	2/0	4.44	4./4	1 /1
independently	2/2	2/0	1/1	4/1	1/1
Engagement in					
classroom					
activies	0/0	0/0	0/0	0/1	0/1
Memory	0/0	1/0	0/1	2/0	0/0
Meal					
preparation	0/0	0/0	0/0	0/0	0/0
Problem					
solving	0/0	0/0	0/0	0/0	1/0
Hand writing	0/0	0/0	0/1	0/0	0/2
Other	0/0	0/0	0/0	0/0	0/0
Other	0/0	0/0	0/0	0/0	0/0



Appendix K

Table 4 represents the frequency of reports by staff members (n=14) regarding what they find it be supportive.

Environment	Staff members
Time management	6
Resources	1
Staff relationship	6
Administration	3
Other	0
Parent relationship	10
Fianances	7
School Material	10
Management style	6
Physical environment	1
government policies	5
Training opportunites	11
Other	0
Other	0

Table 5 represents the frequency of reports by caregivers (n=14) regarding what they find it be supportive in providing care for their child.

Response Item	Frequency
Time management	8
Resources	4
Staff relationship	5
Other	0

Parent relationship	10
Finances	4
Training opportunities	14
Built Environment	6
Government policies	8
Administration	4
Other	0

Table 6 represents aspects of the environment staff (n=14) and caregivers (n=14) find to be supportive to the goal of NAC.

Aspects of the environment	Staff	Caregiver
Management	6	8
Resources	5	2
Staff relationships	8	7
Administration	8	6
Stigma	1	1
Parent relationship	7	10
Finances	7	8
School material	7	3
Ethiopian culture	6	3
Other	0	1
Built environment	6	5
Government policies	6	10
Training opportunities	7	10
Religion	5	4
Other	0	0

Table 7 represents what aspects of the environment staff (n=14) and caregivers (n=14) find to be unsupportive of the goal of NAC,

	Staff	Caregiver	
Environmental aspect	(n=14)	(n=14)	
Management	0	0	
Resources	2	2	
Staff relationships	0	0	
Administration	0	0	
Stigma	4	10	
Parent relationship	0	0	
Finances	1	1	
School material	1	1	
Ethiopian culture	3	5	
Other	1	0	
Built environment	1	3	
2 2 2	_		
Government policies	1	4	
Training opportunities	2	3	
Religion	3	4	
Other	0	0	

Appendix L

Table 78 presents the frequency of reports made by staff members (n=14) and caregivers (n=14), in absolute numbers, of what areas of skill occupational therapists can contribute to.

Q1 111	Staff	
Skill	members	Caregivers
Behavior		
management	8	10
Stress		
management	9	7
Multitasking	6	7
Cognitive skills	8	11
Toilet .	_	
management	7	8
Feeding		
independently	7	7
	-	
Dressing		
independently	7	7
Following	6	10
instructions	6	10
Completing		
school tasks	7	8
Meal	2	
preparation	3	8
Upper limb motor skills	6	43%
IIIOCOI SKIIIS	U	75/0
Hand writing	9	5
Sensory	3	F
management Other	0	5 3
Strict	J	,
Other	0	0

Leisure and		
play	12	8
Learning	11	9
Memory	3	7
Communication		
Skills	4	12
Attention	7	9
Casial abilla	-	12
Social skills	5	12
Making friends	4	9
Following	4	9
routines	5	9
Toutines		<u> </u>
Engagement in		
classroom		
activies	5	8
Cleaning up		
after self	8	8
Academic skill		
advancement	4	9
Problem		
solving	4	9
Other	0	9

Appendix M

Table 9 represents the frequency of reports regarding the top 5 most important areas of skills that an occupational therapist can contribute to. (1 = most challenging and 5 = fifth most challenging). Staff members (n=14)/caregivers (n=14).

CI :II	Rank 1,	Rank 2,	Rank 3,	Rank 4,	Rank 5,
Skills	Frequency	Frequency	Frequency	Frequency	Frequency
Behavior	2/4	0.44	0.40	0.44	0.40
management	2/4	0/1	0/0	0/1	0/0
Stress	2.42	- 1-	- 1-	2.42	- 1-
management	3/0	3/1	0/0	0/0	0/0
NA. dtito obijo o	1 /2	0./0	0./0	0/0	0/0
Multitasking	1/2	0/0	0/0	0/0	0/0
Cognitive skills	0/0	0/0	2/2	1/0	2/0
Cognitive skills	0/0	0/0	3/2	1/0	3/0
Toilet					
Toilet	2/1	0/2	0/0	1 /1	0/1
management	2/1	0/2	0/0	1/1	0/1
Feeding					
independently	1/0	0/0	0/1	0/0	0/0
пиерепиения	1/0	0/0	0/1	0/0	0/0
Dressing					
independently	0/0	0/0	0/0	0/0	0/0
Following	0,0	0,0	0,0	0,0	0,0
instructions	0/0	1/1	0/1	1/0	0/0
IIISTI GETIONS	0,0	1/1	0/1	1,0	0,0
Completing					
school tasks	1/0	0/0	1/0	0/0	0/0
Meal	1,0	3,5	-70	3, 3	3,3
preparation	0/0	0/0	0/0	1/0	0/0
Upper limb	-,-	-,-		, -	
motor skills	0/1	1/0	0/0	0/0	2/0
	,	,	,	,	•
Hand writing	0/0	0/0	3/0	1/0	0/0
	•	•	•	•	•
Sensory					
management	1/0	0/0	0/0	0/1	2/1
Other	0/0	0/0	0/0	0/0	0/0
Other	0/0	0/0	0/0	0/0	0/0
Leisure and	·	•	·	,	•
play	1/0	0/0	0/1	0/0	1/0
Learning	0/0	3/1	0/2	0/0	1/0
Memory	0/0	1/0	0/0	0/2	0/2

Communication					
Skills	0/1	0/1	2/2	1/1	1/1
Attention	0/0	1/0	2/0	1/4	1/4
Socail skills	0/0	0/3	0/0	0/0	1/0
Making friends	0/0	1/0	0/0	3/0	0/0
Following					
routines	0/0	1/0	0/2	0/0	0/0
Engagement in					
classroom	2.42	- 1-	- 1-	- 1-	- 1-
activies	0/1	0/0	0/0	0/0	0/0
Cleaning up	2.42	- 1-	- 1-		- 1-
after self	0/0	0/0	0/0	1/0	0/0
A contouring abili					
Academic skill	1/0	1 /0	0/0	2/0	1 /0
advancement	1/0	1/0	0/0	2/0	1/0
Problem	0/0	0/0	0.40	0/4	0/1
solving	0/0	0/0	0/0	0/1	0/1
Other	0/0	0/0	0/0	0/0	0/0