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Health support services and challenges for west African immigrant mothers of children with special health needs - An interview study in suburban areas in Swedish cities.

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ABSTRACT

Joy., O. (2019). *Health support services and challenges for West African immigrant mothers of children with special health needs - An interview study in suburban areas in Swedish cities*. Bachelor thesis in Public Health Science. Department of Occupational and Public Health Science. Faculty of Health and Occupational Studies. Sweden Gävle University of Gävle.

The **aim** of this study was to investigate and understand how west African immigrant mothers of children with neuropsychiatric disability are been supported by the LSS service providers. **Method:** Qualitative semi-structured interviews were conducted with seven participants, therein four were west African immigrant mothers of children with neuropsychiatric disability and three were LSS service workers. The interviews were transcribed and then thematically analysed. The **Result** shows that there are challenges for the mothers to understand the supportive information because of language barriers, thus making it difficult for the LSS to know whom to provide the structural services to, even though there are no health promotional interventions for the mothers. A total of five main themes and ten subthemes emerged. **Conclusion:** The findings from this study showed that west African immigrant mothers of children with neuropsychiatric disability in Sweden have a cultural perceptions that “disability” is “*outlawed and prohibited*” and their insufficient knowledge on the importance of health literacy affects the LSS from providing rehabilitation and structural interventional services. A suggestion on a social-ecological approach both at micro, meso and macro levels that will enable the mothers and LSS care-providers to achieve a sustainable promotional intervention for better health outcomes in accordance to the Agenda 2030 – *good health for all*.

Keyword: *West African immigrants mothers in Sweden, health and wellbeing, children with neuropsychiatric disorder, Health policy, promotional interventions for immigrant mothers in Sweden.*

Sammanfattning

Syftet med denna studie var att undersöka och förstå hur västafrikanska invandrare mammor med barn med neuropsykiatrisk funktionsnedsättning har fått stöd av LSS-tjänsteleverantörerna. **Metod:** Kvalitativa semi-strukturerade intervjuer genomfördes med sju deltagare, varav fyra var västafrikanska invandrare mammor med neuropsykiatrisk funktionshinder och tre var LSS-tjänstemän. Intervjuerna transkriberades och analyserades tematiskt. **Resultatet** visades att det finns utmaningar för mammorna att förstå den stödjande informationen på grund av språkbarriärer, vilket gör det svårt för LSS att veta vem att tillhandahålla strukturtjänsterna, även om det inte finns några hälsofrämjande insatser för mödrarna. Totalt uppstod fem huvudteman och tio subteman. **Slutsats:** Resultaten från denna studie visade att västafrikanska invandrare mammor med neuropsykiatrisk funktionsnedsättning i Sverige har en kulturell uppfattning att "funktionshinder" är "*olagligt och förbjudet*" och deras otillräckliga kunskaper om vikten av hälsokunskap påverkar LSS från att tillhandahålla rehabilitering och strukturella interventionstjänster. Ett förslag på ett socialt-ekologiskt tillvägagångssätt både på mikro, meso och makronivåer, kommer att göra det möjligt för mödrarna och LSS-vårdgivarna att uppnå en hållbar PR-intervention för bättre hälsoutfall i enlighet med Agenda 2030 - *god hälsa för alla*.

Nyckelord: *Västafrikanska invandrare mödrar i Sverige, hälsa och välbefinnande, barn med neuropsykiatrisk sjukdom, hälsopolitik, stödinsatser för invandramödrar i Sverige.*

PREFACE

Folkhälsostrategi för hållbar utveckling – what a strategic way to preserve the world from further ecological, economical and environmental calamities, thus creating a better sustainable future for generations to come! Thanks to the founders of this programme, Bodil Zackaroff and all my lecturers during this past three years.

There will not be enough thanks rendered to everyone that have voluntarily participated in this project. But I will not fail to thank specially all my interviewees. Through these interviews, I now understand some experiences and thoughts on how west African immigrant mothers and LSS workers feel. The acceptance to be interviewed is a prerequisite for my thesis and without you all, this thesis would not had been possible.

I will like to bestow a big thanks to my family and friends especially my husband and our three lovely children who have always supported and have been patient with me although my three years program, but most especially during the writing of my thesis.

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List of abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
CRPD	Convention on the Rights of Persons with Disabilities
CRC	Convention on the Rights of a Child
EU	European Union
EOPD	Equalization of Opportunities of Persons with Disabilities
HANDISAM	The Swedish Agency for Disability Policy Coordination
HSL	The Health and medical Service Act
ID	Intellectual Disability
LSS	Support and Service to Disabled People
MDGs	Millennium Development Goals
NCDs	Non-Communicable Diseases
SCB	The Swedish Statistic Board
SDGs	Sustainable Developmental Goals
SKOIL	Education Act
SoL	The Social Service Act
UN	The United Nations
WHO	World Health Organization

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1. Introduction

Health inequality amongst individuals in a society leads to social- epidemiological NCDs such as diabetes, cancer, post-traumatic stress, overweight, chronic respiratory diseases (asthma) and ischaemic heart disease (Global burden of disease 2008, p.8). These diseases are leading causes of death globally, killing almost 41 million people yearly (6 out of 10 deaths) which accounts for 71% of the overall 57 million of the yearly death. People from lower/middle- income countries like Africa and Asia faces higher risk of mortality with about 23% of the population dying before reaching the age of 40 years (ibid).

Good public health stands as one of the goals for a better sustainable good health and well-being, and is also a fundamental prerequisite for everyone to fulfil their daily life potential in a society (Sachs 2015: Wheeler & Dawson, 2019 p.4). Public health aims to prevent disease and related disabilities, improve people's lives and promote health care. But one common challenge for every society is the ability to transform the targeted goals into an affordable sustainable health, thus leading to more efforts made by UN to fully eradicate different persistent emerging health inequalities around the world (ibid).

According to UN:s 2016 global health statistics, the world is yet far off in achieving a sustainable health development (United Nation 2016 -Agenda 2030: Sachs 2015). So far, effective actions has been made within Agenda 2030 with intends to offer a more effective sustainable opportunity to influence and improve the health and well-being of every individual globally in or before 2030. In 2015, the UN General Assembly in Resolution A /RES / 70/1 under the name "*Transforming our world*" outlined *eight millennium development goals* (MDGs) that targeted health inequality in developing country like Africa, as well as developed countries including Sweden and England (United Nation 2016 -Agenda 2030). The MDGs was further in 2016 extended to 17 SDGs with 169 sub-goals thereof emerged three sustainable dimensions that influences the microorganisms, human's health and the society. The three dimensions are economical, ecological and social factors that aims at eradicating poverty and empowering good-and equal health into the Public Health policies (ibid). Out of the 17 SDGs, three SDGs are central to the work on sustainable good health and wellbeing, these are: SDG #3 "ensure healthy lives for all" and objective **3.8.1** targets and requires coverage for essential intervention. SDG #5" aims at gender equality and empowering women and girls" , and SDG #16 "promote inclusion in societies lives and to promote a

sustainable well-being for all ages, ethnicity and background”(United Nation 2016). These three SDGs will be used to evaluate the findings in this study.

1:2. Background

1:2:1. Challenges in parenting a child with neuropsychiatric disability as a west African immigrant mother.

“Raising a child is a complex and daunting task; it is a process that encompasses both tradition and the contemporary Zeitgeist.” (Nguyen, Chang & Loh, 2014, p.48).

A public healthcare study done on west African mothers of children with neuropsychiatric disabilities in Canada in 2017, reveals that the mothers’ health and wellbeing deteriorates due to effects of migration and acculturation (Khanlou, N., Haque, Nasim. et. al., 2017; Hastings, R.P., 2003). Nurturers and care-givers such as the mothers are often expected to bring in distinctive good approaches in a child’s upbringing (Khanlou, N. et al 2016; Kvarme, L. G. et. al. 2017). According to Khanlou & Kvarme 2016, it is expected by the African cultures and religious beliefs that mothers have the responsibility to nurture a child and do house chores such as cooking, washing, staying home with the children, etc,. This has made the mothers to build a better bond with their children than their fathers in most west African homes (ibid).

According to studies done by Khanlou, et., al (2017) and Jennings, et., al 2014 respectively on African immigrant mothers who lives in Canada, shows vividly that immigrant mothers of children with developmental disability have perceived that the level of expectations on them in terms of mothering a child is greater because of the responsibilities that are attributed to it (Khanlou, Mustafa, Vazquez, Davidson & Yoshida 2017; Anisa, D., et. al 2011; Jennings, Nazilla & Chang Su 2014), and therefore there are tendencies that these mothers will be care burdens and be emotional stressors for the rest of their lives. However, motherhood according to Khanlou 2017 showed that most mothers are generally joyful to play their roles in the family, but it seems it is taking a negative norm in the society especially amongst immigrant families from west Africa with low educational background, which making motherhood more challenging when there is a child in the family with any form of disability. West African mothers of children with neuropsychiatric disabilities such as autism and ADHD are in most cases held responsible for their children’s attitudes as they are seen as “social problem”(ibid). Hence according to Khanlou, et., al (2017), there are assumptions that

because mothers spend more time with the children, they are therefore blamed for their children's misbehaviour and perceived shortcomings. This is therefore a challenge for most immigrant west African mothers because they feel they are under an observational gaze, thus have to modify their behaviour to fit into the norms of society, which makes the mothers difficult in expressing their emotional feelings, probably because it is assumed no one will understand them (Khanlou., Mustafa, Vazquez, Davidson & Yoshida 2017).

1:2:2 Disability as a complex psychological health need among children - short history.

Health as defined by the World Health Organization (WHO), is "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."(WHO 2008).

Disability defined by WHO 2011 on *world report on disability* “ is part of human condition that has complex multidimensional health concepts from medical, socio-political, economic and administrative perspectives” (WHO 2011, p 3- 4). According to *World report on disability* 2011, there is no consensus about the definition of disability and so it is seen as a dichotomy that limits and restricts physical, mental och intellectual functional abilities in the affected person's life. Hence, people and the society understands malfunctioning and disability as “an evolving concept of dynamic interaction between health conditions (t.ex impairment) and contextual factors such as environmental and social barriers that hinders full and effective participation in the society on an equal basis with others (ibid). There are different types of disabilities/ functional impairments: autism spectrum disorder, impairment of mobility, intellectual disability, hearing or visual impairment, epilepsy, language impairment.

Children with complex psychological health need in this thesis are characterised as those with significant neuropsychiatric disabilities, which is termed as a life- limiting health conditions to any intellectual functioning and maladaptive behaviours such as Asperger, Dyslexia, ADHD, ASD, Tourette's syndrome and ID (S. L. Stewart et al , 2017). These disabilities have negative impacts on both the children and their families. Difficulties such as hypersensitive to sensory stimuli, restlessness, high levels of aggression, physical and domestic violence or abuse both in- and out- of their homes, self- injuries behaviours, communication and learning problem, problem with retaining

and following sensory information, socialisation, as well as their own thoughts on self-care (ibid)

1:2:3. Global health legislation and policy on disability

Following the UNs (2011), CRPD, EOPD and the Public Health legal regulations incorporates and predicates good health conditions in the society by promoting, protecting and ensuring full and equal fundamental human rights for people with disabilities and their families (WHO 2011, p.9). This legislation is applicable both in low- income countries like Africa and Asia, as well as in middle- income or developed European country like Sweden (ibid).

In the perspective of UNs health legislation on disability, Jennings, Khanlou & Su 2014 stated in the *Ontario's Comprehensive Mental Health And Addiction Strategy* that “disabled immigrant children are meant to be a special group and a priority to the population in any governmental agendas”, thus “*disabled children are most poorly linked with the national disability policy agendas*”(Jennings, Khanlou & Su 2014 p.1646). This means that disabled children faces double jeopardy in the social norms and are relatively powerless in the society, therefore are highly marginalized within their families, thus becoming an extra care burden in their families (ibid).

1:2:4. Policy on neuropsychiatric disability in Sweden

Sweden is one of the countries that is at the forefront of policymaking for people with intellectual disabilities worldwide and is a signatory to many UNs conventions. These includes CRPD, CRC and with the cooperation of the Swedish National Board of Health-and Welfare (LSS 9 § 2—10, *Law 2005:125: The National Board of Health and Welfare 2009, 126-188: SOU 2017/18:249*). Sweden as a country has an obligation to follow the signed general principles according to the UN Convention article #3 to meet policies needed to promote children's accessibility and equal of opportunities in life (ibid). In Sweden, LSS, SoL, HSL and SKOIL reinforces opportunities for individuals with disabilities, thus ensuring equal and good living conditions that gives an independent self- determination to people with ADHD, autism, ID and ADD disabilities, as well to families and carers givers. In addition, HANDISAM also has a central role in promoting equal participation regardless of functional capacity (LSS 9 §

2—10, *Law 2005:125*). The Swedish government is in charge of planning, distribution and legislation, as well as social insurance. The local authorities (municipalities) are responsible for social services, and regional government (County councils) are for general health care which provides the framework and objectives of promotive and preventive activities that the municipalities uses according to their own guidelines (ibid).

In 2017 according to the National Board of Health & Welfare, a total of 118 800 intellectual disabled persons were registered in the health data system (The National Board of Health & Welfare, 2018, p. 11: Public Health Agency of Sweden, 2018). This corresponds to about 2% of the 10 000 000 Swedish population, by which over 6% of the 118 800 registered intellectual disabled persons (7 128) are children and youth between the ages of 1- 15 years with prevalence increase of occurrences with psychological diagnoses, hence children aged 0 – 17 years with ASD and ID are estimated to experience “moderate or severe disability at 5.1%”(ibid) .

According to proposition carried out in 2017 by the Swedish Parliament on “*Good and equal health - a developed public health policy*“(SOU 2017/18:249), eight national Public Health goals are targeted in ensuring good wellbeing for all (ibid). In evaluating those eight public health goals, the Swedish government acknowledges health inequalities among the minority groups and thus has an overarching goal aimed to ensure healthy longevity and wellbeing for all – which is in accordance with the targets of the 17 SDGs, “*Good health for all*”. LSS, SoL, HSL and SKOIL understands that people with disabilities are heterogeneous group with tendencies for limitations from easier functioning to extensive difficulties in life, and therefore requires assistance and supports(Public Health Agency of Sweden, 2018: SOU 2017/18:249).

1:2:5. Evidence- based researches on healthcare seeking behaviours among African mothers in Sweden.

According to 2018 Swedish statistics, there are 110 758 African born migrants from Somalia, Asia and west African residing in Sweden (SCB, 2018: The National Board of Health & Welfare, 2018). Over 20 percentage (22 155 persons) of this group are mothers of children with neuropsychiatric disability from western African origin. West Africa comprises of countries such as Nigeria, Ghana, Gambia, Senegal, Cameroon.

Most of these immigrant mothers came to Sweden for different reasons such as in search for safety, a better healthy living, as well as for marriage reunion with family members (ibid).

According to a research made by the Nordic School of Public Health in Gothenburg (NHV 2012), most African immigrant mothers of children with neuropsychiatric disability have because of their children's' disabilities become divorced, thus having care burden to themselves (NHV 2012, p. 27 – 28). The NHV (2012) also expressed that the proportion of children with mainly neuropsychiatric functional impairments living with only their mothers in Sweden are 25% compared to 11% among children without disabilities (NHV 2012, p. 28- 29). This has psychologically affected these mothers with emphasis that 11% of these immigrant mothers have valued their health as poor compared to 4% of the native Swedish mothers. The NHV 2012 also stated that about 12% of immigrant African mothers of children with disabilities tends to have non communicable diseases like diabetes, cancer, asthma, as well as are psychologically and emotional unhealthy (ibid).

With the stress of caring for children with neuropsychiatric disability, most mothers become more vulnerable to be an emotional stressors that can lead to anxiety and hypervigilance (Ijalba, E., 2016; Mangrio, E., & Persson, K., 2017; Anisa, D., et al., 2011). In Sweden, immigrant Africans mothers' health challenges are related mainly on the combination of culture behaviour differences, educational background, social-economic factors, lack of understanding the language, thus not having the accessibility to promotional health supports from the Social services- LSS. Immigrant mothers' ill-health in Sweden is attributed to the negative perceptions and understandings that disability is a precaution of cultural/godly judgement, thus makes these vulnerable mothers socially isolated and reluctant to seek for medical healthcare, and most of the mothers that seeks for medical care, do not seek help in good time (ibid), thus making immigrant Africans mothers of children with neuropsychiatric disability an important study case.

1:3. Study Problem

It is generally understood that there are equality gaps in health and well-being status all over the world, especially among people with disabilities (The global burden of disease, 2008; Khanlou, N., et. al., 2015). Inequality is more obviously seen amongst the minority groups of immigrant mothers of children with disabilities, thus because of low educational literacy and low income. Motherhood expressed by most west Africa immigrant mothers of children with neuropsychiatric disability are that they are having stressful challenges taking care of their children`s hyperactive energies (ibid). Khanlou, N., et. al., 2015 in his study hypothetical (presumed on evidence) proved that stressful challenges can cause on a global range, about 30% of African immigrant mothers within the ages of 25 – 50 years to die untimely. Immigrant African mothers not knowing “where” and not understanding “how” to get the necessary societal health supports needed is the major problem, thereby making this group vulnerable to more health problems through social isolation. what is it that can be done to give this group a sustainable healthcare for their wellbeing?

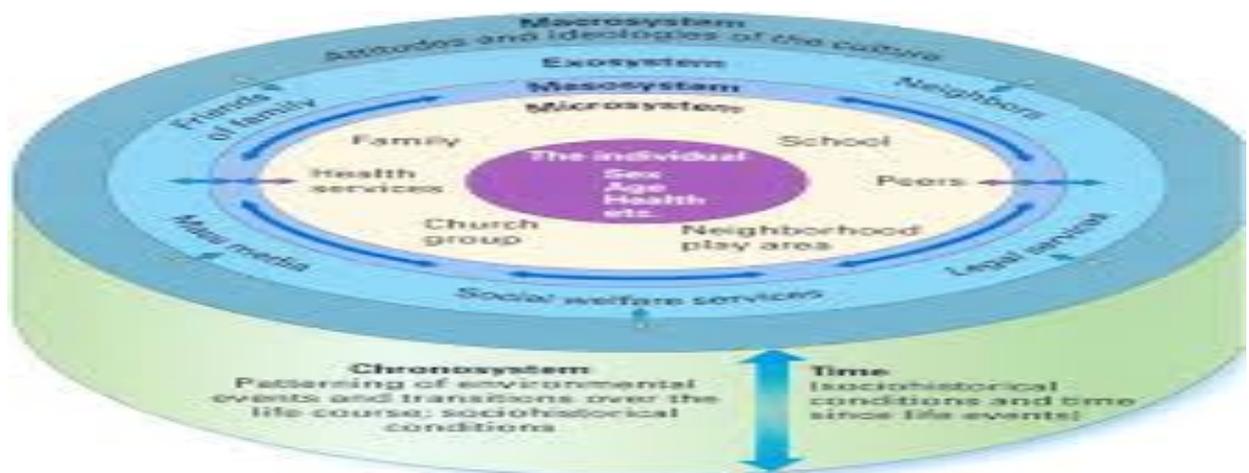
1:4. Aim of study

The aim of this thesis is to investigate and understand how West African immigrant mothers of children with special health needs living in the Stockholm area are supported by service providers.

1:4:1. Study questions

- What health challenges does west African immigrant mothers experience related to having a child with special needs?
- What kind of support services from LSS are available to these mothers and their children?
- How do the mothers access the available support services?
- What acculturation strategies are amendable to the mothers and how can it be implemented?

2. Methodology – Theoretical framework



Bronfenbrenner, 1995 - Socio-ecological model

This study is based on a social-ecological model with resiliency theoretical concept that focus on a contextual approach (Tolley, et. al, 2016, p.34). Social-ecological models (SEM) based on previous studies emphasises that human development is partly dependent on social networks because humans and environment are normally interconnected (ibid). The model has three major contextual levels; the downstream individual level as in the relationships shared between people – such as the relationship between a child and the mother (*microsystem*); the midstream *mesosystem* (*LSS*) which is the interconnection between two or more settings. For example, the relationship between mothers, schools and the government; and the third level is the upstream *macrosystem* that focus on people's shared assumption and sociocultural ideologies. These three socioecological dimensions used as the framework are constitutive process that helped shape immigrant mothers' social identities and simultaneously highlighted transformative health promotions needed. From a transformative perspective, this theoretical framework will help shed more light on the need for modifying and providing social- environmental resources that can enhance individual's wellbeing (Tolley, et. al, 2016, p.34-35).

2:1. Study setting and design

Phenomenological and holistic strategy of in-depth interpretative interviews were used to describe people's experiences and knowledges of their health and well-being (Olsson & Sörensen 2011, p. 180). This study was conducted in Stockholm Sweden, a city with

approximately 900 000 inhabitants, of which over 50 000 are of African origin. The study aimed to understand the challenges west African immigrant mothers of children with special needs encounters in Sweden, thus seven interviews were carried out among four mothers of children with neuropsychiatric disability receiving rehabilitation service. In addition, three care providers were interviewed; two persons from the LSS - Department of Social Service and one manager from a private personal assistance company.

2:2. The Study Participants

Specifically focus was on the immigrant group of western African mothers in Sweden. Participating care-providers had worked in the municipals for at least over two years. Ages of the mothers are ranged between 35 - 45 years and all had received social support from LSS or assistance company during the past 3 years in Sweden. Thus they had enough experiences on interventions needs. Participating mothers had at least three children with one affected with neuropsychiatric disability. Children´s ages ranged between 3 – 17 years old. All names were coded. No children were interviewed.

2:3. Data Collection

This thesis is an exploratory and descriptive qualitative study that describes health context related to sociocultural structures that affects immigrant west Africa mothers of children with development disability, their health outcomes and well-being (Tolley 2016, p.49, 132). Thus seven face- face interviews were conducted and body mapping observations were used in observing the respondents responses, so as to have a better understanding of the experiences from all respondents (ibid). Semi-structured open-ended interviews with flexibility in alteration with probing follow-up questions for more valuable information were used to establish data from care-providers LSS and the care-givers- mothers. Three interview guides were constructed; two interview guides were written in swedish - one for the care providers and one for the mothers, and one interview guide was written in english language for care-givers that did not understand or speak the swedish language (see appendix 3, 4 & 5), and was sent out via mails. This was to minimised the risk of any misunderstandings that could lead to bias information.

2:3:1. Inclusion and exclusion

The procedure for selecting care-providers (LSS) and mothers was done with help of personal network of sending out information letters via emails (see appendix 1 & 2) and by also placing several telephone conversations. A snowball purposeful samplings was used to magnify respondents characteristic but not to generalize it to all populations (Tolley et al., 2016 p.58). Initially fifteen west African mothers and six LSS care-providers were contacted but only three care-providers and four western African mothers originally from Ghana, Nigerian, Senegal and Cameroon accepted to be interviewed. Thus a homogeneous samples on west African immigrant mothers with characteristics and experiences of caring for children with neuropsychiatric disability were selected. Immigrant mothers not from west Africa were excluded. Information and consent letters were sent out to five school principals on their websites. The principals recommended further willing mothers that wants to be interviewed. Snowball purposeful sampling continued when one mother introduces interviewer to another mother for an interview, and then an information letter was sent to them. Participants from the Social services and assistance company were contacted by reaching out also via websites and sending mails. All participants lives and works in and around Stockholm city and in the urban area of one suburb of Stockholm.

2:3:2. Generating data files

A total of eight participants participated in this study. The first was used as a pilot study on mother that has a child with autism , so as to help build up interviewee's confidence, which was helpful for later data collection procedures (Tolley et al 2016, p.158 – 159, 162- 163). A smartphone was used for digital recording in order to get all detailed information and to facilitate the transcription. A notebook was used in writing down important words during interview (ibid). Transcriptions were then transformed into text. Interview time was between 40 - 50 minutes per respondent.

2:4. Data Analysis

Data analysis was carried out in the form of picking apart the interesting and thus the initial sentences encoded (Tolley et al. 2016, p. 176). The data analysis used is a phenomenological-hermeneutical interpretational method which uses template reviews of scientific articles, reports and literatures (Olsson & Sörensen 2011, p. 210-211). A phenomenological hermeneutics analysis can be described as a way of a holistic

interpretation where experiences of respondents are in focus together with the main aim of study, which enables a thematic analysis to be used, and thus maintain focus on the expressed experiences. Thematic analysis is a qualitative research method that is used to identify and analyse interview materials, via the use of coding after transcription of material which can be on either a deductive or an inductive method, but in this case a deductive method was used (ibid). Deductive analysis helps to understand the social-ecological approach theory used in this study.

Interview material analysis was carried out by transcribing all the seven interviews. Tolley (2016) provided steps/ models for data analysis which captures patterns in interpreting interviews into categories, coding, themes, sub-theme and main theme (Tolley et al., 2016, p. 175 – 207), and this model was used in this study.

The contents of the transcribed interview text were analysed with focus on the purpose of the study and research questions, and since the qualitative content analysis is based on what that was said in the interviews, interview coding was grounded in respondents narratives (Olsson and Sörensen, 2011 p. 48, 210). Interpretations were made through the coding process and thematization in the analysis. Focus in this step was to code the text sentences via discourse analysis of the language (Tolley et al. 2016, pp. 179–181: Olsson & Sörensen 2011, pp. 177–178, 180–188), thus most long texts were reduced into short sentences to be able to analyse the most relevant opinions. Body mapping expressions were observed and text sentences were reformulated to be more easily read and well-presented without changing the respondents original expressive meanings. The useful disassembled codes have been synthesized to create an overall picture of the patterns within themes and subthemes (ibid). The coded sentences were used to analyse differences and to find similarities within each code (Tolley et al. 2016, pp. 199-204).

The next step was to analyse the transcribed material, a conventional transcription and qualitative content analysis was made, and the data materials were analysed based on the manifest contents that have more clearly defined text sentences, hence with the latent text sentences that were unclear and misunderstood, the respondents were contacted via mail and asked for further explanations so as to minimise bias information (Olsson & Sörensen 2011, p.210). All analysis were then categorized into different main themes and subthemes (Tolley et al. 2016, pp. 179–181), emerging in total five main themes and ten subthemes acquired both from the mothers and the LSS workers. In the

last step of data analysis, two different tables were used to get an overall picture of the approach that could help present a more in-depth explanation of the data analysis (see appendix 8a & 8b).

2:5. Research Ethics Considerations

This study followed the four ethical principles as recommended by the Scientific Swedish Research Council's book *good research practice*, which is known for its accountability in laws and regulation (Swedish Research Council 2017). Thereby, four ethical principles have been applied during the research process, namely the consent requirement, anonymity, confidentiality and the useful utility of the material requirements. By sending out information and consents letters in advance via e-mail before the implementation of interviews, about how data- material will be stored, processed and used certifies these four ethical principles (ibid). All participants in this study were briefed about the purpose of the study prior the interview started and were also asked whether they accept audio taping, which they all accepted. Participants were given informed consent letters (see appendix 6 & 7) written in both english and swedish; with detailed information on data-use, storage, confidentiality and anonymity and that they could discontinue at any time during the interview, if they felt uncomfortable. To keep the confidentiality of the respondents, data material was anonymous and the names which were selected by the interviewees themselves were coded.

3. Results Analysis

This study's findings are presented into five main themes and ten sub-themes after data material is been transcribed from both the mothers and the LSS care providers (see [appendix 8a & 8b respectively](#)). These themes, codes and categories answers the study's research questions. The themes are: (a) *Socio-cultural beliefs about disability* (b) *Stigmatizations and shame* (c) *challenges to health and wellbeing among mothers* (d) *mothers physical emotional and social sufferings related to language barriers* (e) *Service provider challenges*. The subthemes will be illustrated under the main themes during result analyses.

Theme 1: Socio-cultural beliefs about disability.

Immigrant mothers in Sweden faces ranges of challenges. With the *theme, socio-cultural beliefs about disability* and *subtheme -trust more on their religious beliefs than seeking for healthcare*, expressed that cultural changes and gender roles plays a challenging impact on the mothers' health and wellbeing. One mother expressed that an autistic child is labelled a taboo, outlawed and prohibited, which makes the mother sometimes isolated from the societal activities. Hence this mother felt she has done something culturally wrong and that's why "their gods" punished them with a disabled child.

" I carried the shame and embarrassment of my child's disability for a very long time, the thoughts that my family members or my husband will be pointing blaming fingers at me"..... Even my son's siblings always felt ashamed of their brother's attitude and wouldn't want to go out or sit with him, they do not want people to see them together" - Mother #2.

Another mother expressed feeling lonely and distressed. This was not just about self-perception about disability, but seems like a general perception that disability is a manly caused disease. And so if a disabled child uses a public transport, it is always obvious that people around moves away or laugh at the child's uncontrolled and unpredicted behaviour like loud shouting and tantrums, hence gives reasons for avoiding social gatherings.

"In Sweden there is an ideology to be tolerant to deviants, but i'm not so sure that this ideology is covered by genuine feeling in everyone no one would like to sit next to children with autism or developmental disorder in a restaurant" – Mother#1.

Theme 2: stigmatization and shame

From the study's theoretical meso level, immigrant west African mothers of children with ADD, autism, ADHD, DD in this study explained that the stigma they receive from families, friends and the society because of their child's disability makes them to have lower self-esteem. Language barriers, change in socioeconomic status and lack of support from extended family and social networks are disorienting reversal roles within family settings.

A mother said she was divorced and isolated from her husband's family because ex-husband blamed her African family for bewitching their child, blaming the mother for giving birth to a disabled child with autism. It was expressed by this mother who said that perception has made her to focus mainly on the child, which is in alliance with the *subtheme - poor perception of disability from friends and families makes the mothers stigmatised.*

“ I do not have any man or friends rather than my autistic child because I feel that it is only my child that needs me, and so I have accepted it as it is” I cannot let people's humiliating attitudes affect me anymore because my son is my blood and he is very energetic and needs outgoing activities outside my home ”. Mother#4

It is a complexity of low self-esteem and stigma where traditional beliefs do not acknowledge a child's developmental disability. The lack of family and community support contributes to how poor caregiving west African immigrant mothers deals with their children diagnosis. The chances of vulnerability and socially isolated among these mothers are therefore at a higher rate due to determinant factors such as stigma and perceptions. A mother expressed her feeling with a *subtheme poor perception of disability*, and of such she is now depressed with low self-esteem, negative lifestyles and has physical body pains. Hence keeping her in a complex, contradictory and marginal position (ibid).

“when you have someone who had died, you cry and forget about it! But not autism, it reminds you every day, it is a constant grief. If it is not me who feels sad, then it will be my other children” - Mother #2.

Theme 3: Challenges to health and wellbeing among mothers.

It was observed that the wellbeing of the immigrant west African mothers from this study are negatively impacted as a result of inadequate social structural support. These mothers become exhausted by inadequate level of societal support because all focus lies on the child that is disabled, as alighted in *subthemes- no specific intervention for mothers only... and no holistic family support*. The health and wellbeing for the mothers in this study was tied to opportunities of having a good balance in satisfying their lifestyles such as ability to more physical fitness like jogging, gym training, as well as being socially included in the society.

“I do not have enough time outside of caregiving for my child which has made it virtually difficult for me to socialise and enjoy myself... The only time I feel like going out is when I need to go for massage, that even I cannot do as often as I should because am only entitled to 2000kr per year. My son pushed me and I broke my hip, yet I cannot get as often massage as needed... so am always exhausted with back pains” –Mother#3.

Some other mothers attested to lack of programs and services availability for them, in congestion with the *subtheme- no structural, instrumental, emotional and perceptive support*. Instrumental parenting programs and information session are mainly identified as lacking in the Swedish health system, which LSS care-provider attested to. The programs offered were not convenient locations and did not meet the mothers’ needs.

”...most health programs or workshops teaches only on how to deal with the children, and teaches you nothing on how to deal with yourself” I do not know if the government designed it purposely this way to serve only few people”. The only place you can go is the autism centres where they offer speech therapy and psychologist services, this is only for the child and there is always a long waiting time and when the child is six, they discharge their service and refers you to the hospitals”- Mother #1.

“...according to mother #4, to be healthy mentally, physically and emotionally is something I most desires, but it seems undesirable with my lifestyle because I am diabetic and overweight... for some years now, mother#4 and #2 said they have been diagnosed with cancer, are asthmatic and live with a post- traumatic stress – Mother #4 & mother#2.

Another challenge that these mothers' described was in regards to their health and wellbeing on a meso level. It concerned the lack of social interaction and support, as well as lack of professional knowledge about ADHD, autism, ADD, etc causing them stress. The mothers experienced also a lack of integrated and coordinated services. Thus fragmented and dispersed service made it difficult to them to seek and receive help for themselves.

" I have stayed in Sweden for 14 years and my child was diagnosed when she was 4 years old, I have never heard of any support group for mothers of children with disability. And even if there is any support service, people might not know about it because I have not been properly informed" – Mothers #3 and #4.

*"My son is now 10 years old and had NEVER had any teeth examination in his lifetime because the dentist are scared of being bitten! The doctors will always recommend treating autism med medications like **Strattera** and **metylfenidat** that has sometimes affected the child's sleeps at night. I don't blame them, but if they doctors have a proper knowledgeable strategy about ADHD and autism attitudes and problems, it will be a lesser burden for me or other mothers"- Mother #2.*

Theme 4: Mothers physical emotional and social sufferings related to language barriers.

Miscommunication between the mothers and the care-providers may have arisen from language barriers with *subtheme- bias information misinterpretation*, which have aggravated the mother's frustrations whom experienced physical emotional and social distress related to socio-cultural and language barriers. An significant finding from this study is that these mothers rarely asked for support due to limited knowledge and understanding of how and where to obtain support.

Acculturation and migration is another thing that has negative effects on some of immigrants in Sweden which makes them segregated to a specific environ. African mothers that are accessible to most of the social supportive services in Sweden are mainly from eastern African origin like the Somalians, because the Somalians have a larger inhabitants in Sweden and socialises more than immigrants from eastern African background. Mothers reacts differently to facts in regards to their children's disability,

but all the mothers interviewed had one thing in common – they are all shocked and emotionally down. So, different cultures and beliefs have different views on which emotions can be expressed openly and for how long. Hence it is important that LSS and assistance workers understand this before making decision on supports. In accordance to the interview done with the LSS- worker, Social Service (LSS) and assistance workers seems to apply the same instrumental and supportive interventions on all Africans, probably thinking that all African cultures are the same.

“ It will be needful to understand that all Africans are not the same culturally. A cultural literacy should be highlighted among the LSS-workers” - Mother #2.

All participant in this study attested to health promotion challenges and barriers in structural and perceptive support, which answers the research question #3, *how do the mothers access the available support services?* They all said they had delays in getting diagnosis, long waiting time and excessive paper work, difficulties in navigating the health and social system, lack of awareness and social network, and thus doubts of receiving the support and services they need. There is fragmentation and dispersed services barriers among funded and service providers.

Theme 5: Service provider challenges.

On a macro level, Social service provider like LSS admitted that there is no specific health promotion program mapped out for mothers of children with disability in Sweden irrespective of backgrounds and origins. Mothers have to apply for social support in order for LSS to be able to follow up their health outcome and wellbeing. All LSS and assistance workers interviewed said that the mothers first have to actively seek for support because the Social services - LSS follows regulation and laws that requires an application, but due to the subtheme *lack of effective health literacy* as found during interview, the mothers are reluctant to seek for instrumental and structural supports, thus making it a challenge for the LSS to implement an intervention for their wellbeing. However, according to LSS 9 § 2—10, *Law 2005:125*, LSS provides support to children with disability from ages 1 – 17 years with rights to free education, physical activities and the parents can apply for specialized healthcare via child and adolescent psychiatry (BUP) (ibid).

“Sometimes immigrant mothers find it very difficult to express themselves and so keeps their health challenges a secret. This could be that they do not want to be stigmatised.... but according to the Swedish laws and policy under the Health- and Medical Services Act (HSL), these mothers need to seek for a psycho-social help before they can get one... and so far, none have ever applied for such societal support”- all LSS and assistance workers.

It is challenging for the Social Services and the assistance company to fulfil and implement the basic supportive health promotional services without understanding the specific target groups’ needs and challenges.

“.....Though there has not been any that seek for support, however LSS implemented a cost free program -PRIMA and Crisis- and Discussion Forum- that parents and relatives of persons with disabilities can seek help for treatment interventions within the Rehabilitation & Health. This is where they can get proactive measures like parental education on autism, ADHD, ADD etc ... but most of these mothers hardly comes for any of the programs”- LSS workers #2 and #1

There is not yet a systematic psychosocial intervention described or tested specific among parents of children with disability, but LSS understands the emotional stress the mothers might be undergoing, thus LSS works in association with the Social Insurance and provides personal assistance and allowances for basic needs in every family. Daily life assistance are on average of 20 hours – 24 hours per week and are granted to people with autism, ADD or developmental disabilities depending on the level of disability. This somehow help the families economically.

4. Discussion

From this study's findings, it has become evident that cultural beliefs and language barriers have increased parental distress among interviewed immigrant African mothers, thus lower well-being has ubiquitous effects in them.

4:1 Results discussion

Results from this study has emerged with five main themes: *socio-cultural belief about disability; stigmatizations and shame; challenges to health and wellbeing among mothers; mothers physical emotional and social sufferings related to language barriers; and Service provider challenges*; which have relatively and collectively helped to give more explanations and answers to the study's finding, especially with research questions #1, #2 and #3 that repeatedly emerged during the interviews.

It can be presumed that west African immigrant mothers of children with complex health needs in Sweden tends to suffer from non-communicable diseases such as cancer, post-traumatic stress disorder, anxiety, diabetes typ 2, ischaemic heart disease and to an extent are socially isolated. Based on the *Global burden of disease 2008*, these mothers with these health conditions may be having low self-esteem which is one risk for suicidal mortality (*Global burden of disease 2008, p.8*). In terms of *socio-cultural belief about disability*, the mothers in this study claimed that the main determinant factor for them having lower well-being is first the shock and grief over their children's diagnosis, and then stigmatisation from friends and families due to the negative attitude and cultural perceptions to disabilities.

Considering theme #3-*challenges to health and wellbeing*, amongst immigrant west African mothers of children with special needs, from a health- economic and clinical perspectives, it will cost the Swedish health system economically and socially if these mothers from a minority group develop some NCDs like cancer and post-traumatic stress (The National Broad & Health Welfare 2018, p. 11). The Societal Cost-effect Analysis (CBA) on prevention and promotion of health in good time leads to increased financial benefits and resiliency in the society. In Sweden, a CBA of over SEK 3 million (SEK) is what it costs the hospitals to take care of patients with NCDs like post-traumatic stress, diabetes typ2 and cancer per year (ibid), which are some of the health challenges the studied mothers are having now.

There is obviously a communication and information gap amongst the mothers and the LSS, thus a better communicable aide should be approached according to finding in theme *mothers physical emotional and social sufferings related to language barriers*. In order to alleviate this Public Health problem, a sustainable social structural support need to be establish among immigrant mothers need, for exemple both LSS and the mothers to understand that health and wellbeing is like a human capital of the society (WHO, 2011). Sustainable human capital approach in human life is considered as a normal economic product with a fixed value that can basically help to better individuals wellbeing. These west African mothers could be defined as potential human capitals that needs better knowledge, skills and experiences of health literacy.

The theme *Service provider challenges* is in accordance with what all LSS and assistance workers interviewed expressed, that there are no previous studies relating to supportive services received by mothers of children with special needs, however, children with disability from ages 0 – 17 years have the right to free education, physical activities and can apply for specialized healthcare via child and adolescent psychiatry (BUP). This subsidy would help many of the mothers in terms of economical supports, but these mothers seems to need more than just economical supports for themselves.

According to the findings from this study, there is need for physical fitness and socializing among west African immigrant mothers of children with neuropsychiatric disability. Structural interventions seems to be a sustainable solution in filling the inequality health gaps amongst LSS and the mothers. Supports such as social networking on fundamental information and awareness should be used to identify both positive and negative consequences that influences society (LSS) and her population (the mothers). From the Khanlou 2017 study, it was well understood that a good social interventional network of support from both micro, meso and macro helps in improving the health literacy of immigrant mothers of children with neuropsychiatric disability (Khanlou., Mustafa, Vazquez, Davidson & Yoshida 2017), with highlights on the importance of managing and coping with stress by reducing psychological distress that comes with taking care of children with neuropsychiatric disabilities. This means that the physical, socioeconomical and cultural dimensions that influences these immigrant African mothers' health outcomes such as mental and physical health status and wellbeing needs promotive strategies (ibid).

From a Public Health strategic within a sustainable perspective and based on the explanations received from all seven interviewees, it is obvious that interventions from an upstream (macro) midstream (meso) and downstream (micro) strategies need to be implemented, to be able to meet the three SDGs that this study highlighted in the introduction, that is: SDG #3 “ensure healthy lives for all”, SDG #5” aims at gender equality and empowering women and girls”, and SDG #16 “promote inclusion in societies lives and to promote a sustainable well-being for all ages”. With this purpose, two different interventional suggestions have been mapped out by the interviewer (me) for both the mothers and the Social service providers, that improves supports that allows people to achieve full health potentials. These are:

Interventions needed from the perspective of the mothers

- The Social service and assistance companies need to reassure immigrant mothers of children with complex health needs of the supports available for them and how they can access it. This will make the mothers trust the system again and thus feel free in seeking for support from the LSS and assistance companies.
- Health literacy which is a clearer knowledge of the importance of health need to be implemented – Mothers acquires the basic Swedish language by going to SFI.

Intervention for the Social Service

- Organising seminars with different languages by training health care providers to be culturally competent and diversity.
- Put a regular check-up on the mothers. They are dealing with post-traumatic stress disorder, and so will be nice to understand that economically support does not take away the pain – they need to show them empathy and create more abilities to physical activities is essential.
- Create a reachable communicable forum where other mothers that have the same experiences can share and encourage others, tex via Facebook etc
- Have a better co-operation with other countries and companies that have successfully helped the case study which will help the mothers achieve positive health effects which is in accordance with the 17 SDG and the Swedish “*Hälsa 2020*” – *filling the inequality gaps before 2030*.

4:2 Methodology discussion

As mentioned, this study is an exploratory and descriptive qualitative method, which aims to understand the challenges west African mothers of children with neuropsychiatric disability. The concept of reliability and generalisability are used to assess the qualities of qualitative researches. In a broader sense reliability and validity refers to the “goodness of measurements” that a researcher followed (Tolley, 2016, p. 206). Reliability concerns the consistency and trustworthiness applied in the study’s measurement such that can yield the same result when done by another researcher, while generalisability refers to the degree to which the study’s results can be applied in other future contexts.

To evaluate the reliability of this study, dependability, transferability, credibility and confirmability were taken into consideration (Tolley et al. 2016). Dependability here is to reduce interpretation errors during thematicization and coding. The method implemented has a transferability context, such as during the transcription process, verbatim transcription was followed, which means that all interviews were done in calm environment, thus did not encounter any sound barriers. Analytic generalisation rests upon adequate contextual description and understandings provided by my research and then transferred to different themes, codes and categories. To enhance trustworthiness, confirmability and credibility, peer-review of previous studies and respondents validation were applied according to Tolley 2016. This means that during the interview guide construction, several confirmatory open questions were used to validate the consistency of all respondents’ answers. To minimise study biases, direct leading questions were avoided, which are often said to reduce the reliability of qualitative researches. This helped in getting visible and reliable facts to validate the results of the study (Tolley, 2016, pp. 206 - 208).

4:2:1 Study Limitations – further research

Strength: There is a possibility that positive results will be reached if further studies are carried out, because both the care-giver(mothers) and the care-providers are willing to fill in the gap among them. If we encourage further researches, the increased risk of occurrence prevalence of non-communicable diseases will be reduced, thus an increase in socialising and healthy wellbeing will be more radiant in the society.

Weakness: This study has encountered some limitations. This study only relied on information received by data secured in-depth face-to-face interviews of only seven

participants. However, it will be admitted that the inclusion of other qualitative methods such as focus group discussion would have yielded better results and get better understanding to the aim of study, but because of the duration of the course and that participants live in different districts and they work in different places, that target was not met. The mothers in this study are all limited to a specific geographical area in Sweden, thus may not necessarily be representative to all African immigrant mothers of children with neuropsychiatric disabilities in Sweden. Another limitation stem was to select only mothers, significant comparative limitation is the exclusion of African immigrant fathers of children with special health need. Further quantitative studies should be done on a broader population scale in order to get a better validated understanding and result.

4. Conclusion

The findings of this study have fulfilled the aim and objective by identifying the major challenges most west African immigrant mothers of children with neuropsychiatric disability may encounter in Sweden. All the mothers in this study expressed gratitude about receiving a better healthcare compared to what they would have received in their home countries. However, it is evident that most west African immigrants mother's health and wellbeing in Sweden still needs more clinical and social interventions both on macro, micro and meso socioecological levels.

It cannot never be over emphasised that health literacy is an important intervention which need to be implemented among immigrant west African mothers in Sweden. The mothers should be encouraged to study as least the swedish language at SFI level, this will help them understand more the consequence of their health negligent and as well be able to communicate well with the authorities for supports and get better health outcomes.

This study's finding is hoped to be helpful in many ways. Firstly, that care providers (LSS) will have a broader and better knowledge about the need for more health promotional strategies to empower their already mapped interventions for people with disabilities and their families. Secondly, health workers and practitioners working with immigrant children and mothers will gain better understanding on how to deal with intercultural family's backgrounds and as well generate a sustainable means of reaching

out to these group of people. Thirdly, it will re- encourage immigrants African mothers of children with special needs that the society understands their emotional pains and are willing to help in empowering their self- esteems, self-efficacy and wellbeing, such that accomplishes the aim and goals of SDGs – “*Good health for all*”.

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Appendix 1 - Information Letter

March 2019.

My name is Joy Offor and I am studying public health strategy focusing on sustainable development at the University of Gävle. I am writing my third year thesis which aims to observe and understand how ethnic West African mothers to children with neuropsychiatric disabilities are supported by Swedish Social Service. Many people with foreign backgrounds find it particularly difficult to meet their own health needs. Therefore, my ambition is to have/create a better understanding to support needs of this specific group of mothers. My study also aims to obtain an overview of the support programmes available to this group and how the support is implemented.

In total 4- 6 mothers who have received or are receiving support from LSS (Support and service to disabled by Social Services) will be interviewed individually.

In addition, 1 – 2 interviews will be conducted with employees at the LSS department of Social Service. Each interview will take no longer than 55 minutes, and will be audio recorded and later transcribed.

Participation in this study is voluntary and will comply with Swedish ethical research regulations which includes the following requirements. Participant is voluntary with rights to withdraw at any time without explanation. A signed written consent form confirms voluntary participation. All recorded and transcribed materials from the interview will be kept confidentially. Names and personal details will be decoded. The information received from participants during the interview will only be used for study purposes.

This thesis will be published in the DiVA database and accessible there. Four ethical research rules according to the Science Council Broad will abided. If you have any questions or concerns, please do not hesitate to contact me through the following email address: samansheart@yahoo.co.uk or call me at 0760101069.

Thanks in advance!

Yours sincerely,

Joy Offor (*Future public health strategy for sustainable development*).

Appendix 2 Informationsbrev

Mars 2019.

Jag heter Joy Offor och jag studerar folkhälsostrategi med fokus på hållbar utveckling vid Gävle universitet. Jag skriver mitt tredje års avhandling som syftar till att observera och förstå hur etniska västafrikanska mödrar till barn med neuropsykiatriska funktionshinder stöds av svensk socialtjänst. Många med utländsk bakgrund tycker det är särskilt svårt att uppfylla sina egna hälsobehov. Därför är min ambition att ha / skapa en bättre förståelse för att stödja behoven hos denna specifika grupp mödrar. Min studie syftar också till att få en översikt över de stödprogram som är tillgängliga för denna grupp och hur stödet genomförs.

Totalt kommer 4-6 mammor som har fått eller får stöd från LSS (support och service till funktionshindrade av socialtjänsten) intervjuas individuellt.

Dessutom kommer 1 - 2 intervjuer att genomföras med anställda vid LSS-avdelningen för socialtjänsten. Varje intervju tar inte längre än 55 minuter och kommer att inspelas och senare transkriberas.

Deltagande i denna studie är frivillig och kommer att följa svenska etiska forskningsregler som innehåller följande krav. Deltagaren är frivillig med rätt att återkalla när som helst utan förklaring. Ett undertecknat skriftligt samtycke formulär bekräftar frivilligt deltagande. Alla inspelade och transkriberade material från intervjun kommer att hållas konfidentiellt. Namn och personuppgifter kommer att avkodas. Informationen från deltagarna under intervjun kommer endast att användas för studieändamål.

Denna avhandling kommer att publiceras i DiVA-databasen och tillgänglig där. Fyra etniska forskningsregler enligt Vetenskapsrådet kommer att följa. Om du har några frågor eller frågor, tveka inte att kontakta mig via följande e-postadress:

samansheart@yahoo.co.uk eller ring mig på 0760101069.

Tack på förhand!

Med vänliga hälsningar,

Joy Offor (Blivande folkhälsostrategi för hållbar utveckling).

Appendix 3 Interview questions for mothers of children with complex health needs

General and Demographic Questions

- ❖ May i ask you, how old are you?
- ❖ Which country do you come from?
- ❖ Can you tell me about your educational background?
- ❖ How long have you lived in Sweden?
- ❖ How would you describe your knowledge of the Swedish language?

Family situation

- ❖ Are you single, married, widowed or divorced?
- ❖ How many children do you have? Can you tell me about your child(s) gender and age?
- ❖ How many of your children have special health needs (neuropsychiatric)? Which of your child?
- ❖ What kind of special needs/disability does your child have?
- ❖ How long has your child had this special health needs/disability - was it before or after arriving in Sweden?
- ❖ Who in the family takes care of child with special health needs?
- ❖ Have you ever felt that you were treated differently in public or social situations because your child has this disability?

Social service support needs

- ❖ What support do you have/need as a mother of special needs child(ren)?
- ❖ Can you describe what support do you need for your own health and wellbeing?
- ❖ How do you think that the social services best support mothers of a special needs child(ren)?
- ❖ What additional support do you think could help mothers of special needs children?

Informational and received social service support

- ❖ What support have you received in the past 6 months – 1 year from the social services for your special needs child(ren)?
- ❖ What support have you received for yourself to help you lessen the stress on you?
- ❖ Can you explain how the support you receive(d) is helpful to yourself and your special needs child(ren)?
- ❖ How accessible is the available information/ support on functional disabilities and rehabilitation to you, your child and family? Exemple on how LSS, autism centres, doctors and schools can help you?
- ❖ How convened is the accessible support for you and the family? (time, place, cost etc)
- ❖ What do you think are the major challenges for mothers of special needs children to access information about available supports? How can it be improved if need be?

Health promotion support

- ❖ How has your child's diagnosis affected your health and well-being? Exemple your self-esteem and your personality. Did you seek help?
- ❖ Can you share any special experience where you have felt emotionally down and depressed?
- ❖ Have you or are you receiving any health promotion support as a mother of a special needs child(ren)? Exemple where you can go for therapy, massage, training etc.
- ❖ Was/ is the health promotion support helpful? If yes, in what way?

- ❖ What other support do you think you would benefit from the social services but isn't currently available to you?

Other

- ❖ Do you want to add anything more? Do you have any more suggestions/ comments.

Thanks for participating!

Appendix 4 - Intervjufrågor för mödrar av barn med komplexa hälsobehov

Allmänna och demografiska frågor

- ❖ Kan jag fråga dig, hur gammal är du?
- ❖ Vilket land kommer du ifrån?
- ❖ Kan du berätta om din pedagogiska bakgrund?
- ❖ Hur länge har du bott i Sverige?
- ❖ Hur skulle du beskriva din kunskap om det svenska språket?

Familjesituation

- ❖ Är du singel, gift, änka eller skild?
- ❖ Hur många barn har du? Kan du berätta om ditt barns kön och ålder?
- ❖ Hur många av dina barn har speciella hälsobehov (neuropsykiatriska)? Vilket av ditt barn?
- ❖ Vilken typ av speciella behov / funktionshinder har ditt barn?
- ❖ Hur länge har ditt barn haft denna speciella hälsobehov / handikapp - var det före eller efter ankomsten till Sverige?
- ❖ Vem i familjen tar hand om barn med speciella hälsobehov?
- ❖ Har du någonsin känt att du behandlades annorlunda i offentliga eller sociala situationer eftersom ditt barn har denna funktionshinder?

Behov av socialt stöd

- ❖ Vilket stöd har du / behöver som barn för särskilda behov barn?
- ❖ Kan du beskriva vilket stöd du behöver för din egen hälsa och välbefinnande?
- ❖ Hur tycker du att socialtjänsten bäst stöder mammor i ett barn med särskilda behov?
- ❖ Vilket ytterligare stöd tycker du kan hjälpa mödrar till speciella behov barn?

Informations- och mottaget socialtjänststöd

- ❖ Vilket stöd har du fått under de senaste 6 månaderna - 1 år från socialtjänsten för ditt speciella behov barn?
- ❖ Vilket stöd har du fått för dig själv för att hjälpa dig att minska stressen på dig?
- ❖ Kan du förklara hur det stöd du får (d) är till hjälp för dig själv och ditt barn med särskilda behov?
- ❖ Hur tillgänglig är tillgänglig information / stöd för funktionshinder och rehabilitering till dig, ditt barn och din familj? Exempel på hur LSS, autismcentra, läkare och skolor kan hjälpa dig?
- ❖ Hur sammankallas är det tillgängliga stödet för dig och familjen? (tid, plats, kostnad mm.)
- ❖ Vad tycker du är de största utmaningarna för mammor i särskilda behov, barn att få tillgång till information om tillgängliga stöd? Hur kan det förbättras om det behövs?

Hälsofrämjande stöd

- ❖ Hur har ditt barns diagnos påverkat din hälsa och välbefinnande? Exempel på självkänsla och din personlighet. Sökte du hjälp?
- ❖ Kan du dela någon speciell upplevelse där du känner dig känslomässigt ned och deprimerad?
- ❖ Har du eller får du något hälsofrämjande stöd som mamma till ett barn med särskilda behov? Exempel där du kan gå till terapi, massage, träning etc.
- ❖ Var /är hälsofrämjande stöd till hjälp? Om ja, på vilket sätt?
- ❖ Vilket annat stöd tror du att du skulle ha nytta av de sociala tjänsterna, men är inte tillgänglig för dig idag?

Övriga

- ❖ Vill du lägga till något mer? Har du några fler förslag / kommentarer.

Tack för att du deltar!

Appendix 5 Intervjuguide till Vårdgivare - LSS

Inledning frågor

- ❖ Hur många medarbetare är ni som arbetar med målgruppen mammor med afrikanskt ursprung som har barn med neuropsykiatrisk funktionsnedsättning?
- ❖ Vilket yrkesroll har du?
- ❖ Hur länge har du arbetat med den här målgruppen?
- ❖ På vilket sätt arbetar ni med stöd till mödrar/föräldrar till barn med någon form av neuropsykiatrisk funktionsnedsättning?

Frågor om stödinsatser

- ❖ Hur initieras ett ärende med råd och stöd för barn med neuropsykiatrisk funktionsnedsättning – från regeringen (beslutare) till föräldrarna (respondent/patient)?
- ❖ Vilka organen ansvarar/ stödjas mammornas hälsa?
- ❖ Vilket stöd erbjudas dessa mammor?
- ❖ Vilka skillnader finns i stödet till etniska svenska mammor och mammor med afrikanskt ursprung? Om det finns ingen skillnader, tror du att stödinsatser är jämt för alla?
- ❖ Hur skulle du beskriva det stöd som erbjuds mammor från afrikanska länder med funktionsnedsatta barn?
- ❖ Hur skulle du jämföra stödet till mammornas gruppen från afrikanska länder med annat ursprung?

Förståelser om mammornas svårigheter

- ❖ Vilket information får mammorna om det stöd som finns gällande deras barn? Till exempel, om vilka typ av mat kost barn med autism kan ha eller inte?
- ❖ Vilket information får mammorna om det stöd som finns för de själva? Tex deras rättigheter till något hälsofrämjande aktiviteter?
- ❖ Vilka behov anser du att mammorna har gällande hälsoråd och stöd?
- ❖ Vad görs för att förbättra mammornas kunskap och överblick av förståelse för funktionsnedsättningar? kan du ge några exemplar?
- ❖ Anser du att assistanserna behöver förbättras? På vilket sätt?

Frågor om interventioner

- ❖ Kan du beskriva hur ni planerar och samordnar stödet för den här målgruppen? Till exempel, från när barnet blev diagnoserad tills föräldrarna får något assistans.
- ❖ Erbjuder ni mammorna några aktiviteter för att förbättra deras hälsa?
- ❖ Använder ni några specifika hälsometoder för att stödja mammorna? Vilka?
- ❖ Hur tillgängligt skulle du säga att stöder är till mammorna?
- ❖ Hur implementeras/ utvärderas och uppföljs stödinsatserna?
- ❖ Vilka är de största utmaningarna när det gäller stöd till mammorna?

Är det något mer du skulle vilja tillägga?

Stort tack för medverkan!

Appendix 6

Informed Consent

Below you give your consent to participate in the study in which Joy Offor, a student at the University of Gävle, is conducting a study on how West Africa mothers of children with neuropsychiatric disorders receive support by social services in a Stockholm suburb. Read this carefully and give your consent by signing your name at the bottom of this page.

Consent

- I have received information about this study and I am aware of how and when it is conducted.
- I have had the opportunity to have my questions regarding the study answered before the interview starts and I know who I can contact if I have any further questions.
- I participate in this study having been informed about its purpose.
- I am aware that I can cancel my participation at any time during the course of study without having to explain why.
- I give my consent to how the information is collected during the interview as well as how the information will be processed and stored after the interview.

Stockholm April, 2019.

.....

Name

Signature

Thank you for participating!

Appendix 7 – Samtycke till deltagande i uppsatsstudie

Nedan ger du ditt samtycke till att delta i den studie där jag Joy Offor, student på Högskolan i Gävle undersöker om hur Västafrika mödrar av barn med neuropsykiatriska störningar i en Stockholms förort får stöd av sociala tjänster för att hantera deras välbefinnade hälsa.

Läs igenom detta noggrant och ge ditt medgivande genom att skiva under din namnteckning längst ned.

Medgivande

- Jag har tagit del av information kring studie, är medveten om hur den kommer att gå till och den tid det tar i anspråk.
- Jag har fått tillfälle att få mina frågor angående studien besvarade innan den påbörjas och vet vem jag ska vända mig till med frågor.
- Jag deltar i denna studie helt frivilligt och har blivit informerad och vad syftet med studien är.
- Jag är medveten om att jag när som helst under studiens gång kan avbryta mitt deltagande utan att behöva förklara varför.
- Jag ger mitt medgivande till att lagra och bearbeta den information som samlas in under studien.

Jag ger detta medgivande förutsatt att inga andra än student och den handledare som är knutna till studien kommer att ta av del av det insamlade materialet.

Stockholm den..... April, 2019

.....
Namnteckning

.....
Namnförtydligande

Tack för medverkan!

Appendix 8a

Result from study's data collection

Table 1:1 Theme, codes and categories identified in among mothers.

Theme	Sub-theme	Categories	Codes
Language and social interaction barrier	Misunderstanding and misinterpretation of interventional programs	*mother's understating Social services	Information in only Swedish and too advanced for immigrants
Lack of social intervention and resources	Feels like no one cares. Not socially included	*mothers find it difficult navigating the health and social systems	Socially isolated
Lack of programs and services	No structural, instrumental, emotional and perceptive support	*All programs are focused on the children	Support with finances is not all that is needed.
Lack of trust as a barrier to access service	Delay in diagnosis for children, lack of awareness of client needs by service providers. No holistic family support.	*fragmented and dispersed service. *mothers dissatisfaction on the discordance between health, school and social service	Create health promotional programs and support group.
Stigmatisation and low self-esteem due to no self-agency or advocacy	Poor perception of disability from friends and families	*Need good health literacy	Need independent lifestyle and empowering
Low healthcare outcome	Diagnosed for cancer, sleepless nights, partially paralyzed	*Divorced and only custody practice	Doubt receiving support and services for themselves from LSS.

Appendix 8b

Table 1:2 Themes, codes and categories from care-provider

Theme	Sub-theme	Categories	Codes
Language barrier	Bias information misinterpretation	Distant communication technology	Difficulty deterring information
Health system effect	No specific intervention for mothers only, but instead for the whole family. Health illiteracy hinders mothers from support and services for them. Misconception about Social service provider.	Immigrant mothers sought no healthcare personally for themselves	Immigrants attitude
Acculturation and religious influence on disability	Trust more on their religious beliefs than seeking for healthcare. Challenging to adapt to Swedish culture in healthcare	Believe psychiatric diagnoses is a related to impurity and shame.	Keeps their health conditions a secret.
Lack of effective health literacy	No clearer knowledge on the services.	Need for better health promotion services for immigrant mothers	Increase and improve changes to receive equal healthcare.