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# Somalian families' views on disabled children and Finnish health care services

Starck, Jenny

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# Somalian families' views on disabled children and Finnish health care services

Jenny Starck
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Jenny Starck

**Lapsen vammaisuus ja Suomen terveydenhuollon palvelut somaliperheiden näkökulmasta**

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Lisääntynyt maahanmuutto ja monikulttuurisuus näkyvät Suomen terveydenhuollossa, ja somalit edustavat yhtä suurimmista kulttuurivähemmistöistä erityisesti pääkaupunkiseudulla. Tutkimuksessa tarkastellaan Suomessa asuvien somalitaustaisten vanhempien kokemuksia heidän erityislapsensa hoidosta ja kuntoutuksesta Suomen terveydenhuollossa. Lisäksi tutkimuksessa tarkastellaan somalivanhempien ajatuksia siitä, miten somalitaustaisten perheiden, joilla on erityistä tukea tarvitseva lapsi, hoito- ja kuntoutuspalveluita voitaisiin kehittää. Tutkimuksessa on selvitetty myös somalivanhempien kokemuksia kulttuuristen näkökohtien huomioimisesta Suomen terveydenhuollossa sekä sitä, mitä vammaisuudesta ajatellaan somalikulttuurissa. Tutkimus on toteutettu yhteistyössä vammaisten maahanmuuttajien tukikeskus Hilman kanssa ja sen tarkoitus on palvella erityisesti Hilman, mutta myös terveydenhuollon ammattilaisten sekä somaliperheiden tarpeita.

Teoriaosassa keskitytään somalikulttuurin keskeisimpiin piirteisiin sekä somalialaiseen käsitykseen terveydestä ja vammaisuudesta. Teoriaosuudessa luodaan katsaus myös Suomen terveydenhuoltojärjestelmään, vammaisen lapsen hoito- ja kuntoutusmahdollisuuksiin sekä suomalaisiin vammaisuuden käsityksiin. Tutkimuksessa on noudatettu laadullista tutkimusmenetelmää. Tutkimusaineiston saamiseksi on haastateltu neljää somalitaustaista vanhempaa, jolla on erityistarpeita vaativa lapsi; kolmea äitiä ja yhtä isää. Lisäksi somalin kielen tulkkia sekä somalikulttuurin asiantuntijaa haastateltiin syventääkseni ymmärrystäni kulttuuriin. Haastattelut on toteutettu kesän ja syksyn 2016 aikana. Aineisto on analysoitu sisällönanalyysin menetelmällä.

Tutkimustulokset osoittavat, että Suomessa asuvat somalitaustaiset vanhemmat kokevat Suomen terveydenhuollon palvelut ja ammattitaidon erittäin hyviksi vammaisen lapsensa kohdalla. Somalivanhemmat kokevat, että terveydenhuollon henkilökunta on kunnioittanut heidän kulttuuriaan, ja tulkkeja on käytetty tarvittaessa. Vaikka tutkimukseen osallistuneet vanhemmat kokevat vammaisten lastensa terveyspalvelut hyviksi, myös kehittämisehdotuksia nousi esiin: vanhemmat kaipaavat eri terveydenhuoltoalan ammattilaisilta tiedotusta sekä Suomen terveydenhuollosta että erilaisista lasten kehityksellisistä pulmista ja hoitomahdollisuuksista. Tutkimusta tehdessä ja haastatteluista nousi esiin, että vammaisuus koetaan hyvin häpeälliseksi ja arkaluontoiseksi asiaksi somalikulttuurissa.

Tutkimuksen johtopäätös on, että somaliperheitä, joilla on erityistä tukea tarvitseva lapsi, tulisi tiedottaa Suomen terveydenhuollosta sekä sen palveluista. Lisäksi on tärkeää tiedottaa lasten erilaisista kehityksen pulmista, jotta somalit saataisiin paremmin palveluiden piiriin ja vammaisuutta koskeva häpeä vähentyisi. Tuloksia tarkasteltaessa on hyvä pitää mielessä, että tutkimus on tapaustutkimus ja tulokset edustavat neljän somalivanhemman kokemuksia.

Asiasanat: Somali kulttuuri, Vammainen lapsi, Suomen terveydenhuolto, Kuntoutus

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Jenny Starck

**Somalian families' views on disabled children and Finnish health care services**

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The increasing flow of immigration calls for renewal in the Finnish health care system. Somalis are one of the biggest cultural minorities in the metropolitan area. The aim of this study was to examine the experiences of the Finnish Somalis on the health care and rehabilitation services provided for their disabled children. Additionally, the study aimed to find ways to improve the current services. The cultural aspects and views on disability were also an important theme in this study. The study was conducted in cooperation with Hilma – The Support Centre for Immigrant Persons with Disabilities. Thus, the purpose of this study was to serve the needs of the Hilma organizations as well as those of health care professionals and Somali families.

The theory section focused on the main aspects of the Somali culture as well as views on health and disability. It also introduced the Finnish health care system and the way health care and rehabilitation services are organized for disabled children, as well as Finnish cultural views on disabilities. The qualitative data of this study consisted of four individual interviews, which included three Somali mothers and one father. In addition, a Somali interpreter and a Somali culture specialist were interviewed in order to gain knowledge on the Somali culture. The analysis part of this study focuses on the interviews of the Somali parents. The data was gathered during the summer and autumn of 2016. The data was analyzed with the content analysis method.

The findings of this study indicated that the experiences of the Somali parents on the Finnish health care and rehabilitation services for disabled children, as well as on the proficiency of the health care professionals, were very positive. The Somali parents also feel that their culture has been treated with respect, and interpreters have been utilized when necessary. Even though the Somali parents' experiences on the health care and rehabilitation services were positive, room for improvement was found. Firstly, the Somali parents require more information on the Finnish health care system, children's developmental delays as well as potential care and rehabilitation methods. In addition, it was found that in the Somali culture, disability is considered a very shameful and sensitive topic.

The conclusion of this study was that informing Somali families with a disabled child about the Finnish health care system and the services provided should be improved. Additionally, it is important to deliver information related to children's neurological challenges. The findings of this study are essential in placing disabled Somali children into the right health care services, and to lessen the shame toward disability. It is important to note that this was a case study and therefore the results represent the views and experiences of four Somali parents only.

Keywords: Somali culture, Disabled child, Finnish health care, Rehabilitation

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# 1 Introduction

Migration and immigration are rising rapidly around the world, and also Finland now has more immigrants, refugees and asylum seekers than ever before (Finnish Immigration Service 2015). Also today, people move and travel more than before (Castles et al. 2003). The foreign population of Finland has almost doubled in the 2000s. According to the Ministry of Social Affairs and Health (2015), there are many reasons for the migration of people, for instance some people travel because of their own interest and will, and some are escaping a war or political conflicts in their home countries (Ministry of Social Affairs and Health 2015). According to various reasons, multiculturalism is an increasingly discussed topic worldwide (Ministry of Education and Culture 2015). Somalis are a significant immigration group in the country (Statistics Finland 2015). The number of Somali speakers has been constantly increasing in Finland. In 2000, less than 7 000 people spoke Somali, compared to 2015 when almost 18 000 people spoke Somali language. (Statistics Finland 2015.) This means that Somali is the fourth largest language minority in Finland today (Finnish Immigration Service 2015). Furthermore, Somalis are one of the biggest immigrant groups in Finland today, and as the instability in Somalia continues there will be a steady stream of Somali refugees coming to Finland (Pentikäinen 2005). In addition, Somalis are the largest Muslim background immigrant group in Finland (Mölsä & Tiilikainen 2007, 451).

There are many Somalis in Finland who do not have Finnish citizenship. According to Finnish Immigration Service (2015), approximately half of the Somalis living in Finland have Finnish citizenship. This amount includes also Somalis who were born in Finland. However, Somalis are one of the largest immigrant groups to have been granted Finnish citizenship. (Finnish Immigration Service 2014.) Somalis in Finland are demographically quite a young population. Most of the Finnish Somalis are children, and only about 250 Somalis are over 65 years of age. (Statistics Finland 2015.) Somali culture is very visible in Finland and therefore it is also seen in the Finnish health care sector.

According to Varis (2011) the internationalization applies to everyone. As the world is changing, also the health environment is constantly changing and facing new challenges. The rapid increase of foreigners has also affected the Finnish health care and rehabilitation services. As healthcare workers, we are practicing our trade in an increasingly multicultural environment. I consider it highly important that health care professionals take the cultural matters into account when dealing with customers from other cultural backgrounds.

Understanding the possible pitfalls and possibilities with other cultures allow us to work more effectively. The ability to understand different cultures is important and even necessary for many health care professionals, because of the multicultural health care and rehabilitation service users. Somalis are one of the biggest foreign cultural groups in Finland, and therefore Somalis also represent major health care service users, particularly in the metropolitan area (Mölsä & Tiilikainen 2007, 451).

Additionally, as described in a report of the Finnish Immigration Service (2015), children in immigrant families represent an important and growing group of the overall child population in Finland (Finnish Immigration Service 2015). Furthermore, approximately 10 per cent of the immigrant children in Finnish day care need some kind of special care (Sarvimäki & Kangasharju 2006.) This was the starting point of the thesis: to improve disabled Somali children's' health care and rehabilitation services.

The chosen research topic is very current and important, especially from the health care sectors, and the Somali immigrants' point of views. As the immigration is constantly increasing around the world, I find improving and developing the services for immigrants very important and ethically essential. In addition, the reason behind the chosen topic was my motivation to combine my profession as an occupational therapist, and my special knowledge, experience, and interest in children's neurological problems to a relevant topic of immigrants' rights in Finland.

In my job I encounter multicultural families, particularly Somali families regularly. I have encountered the lack of cultural knowledge by the health care professionals and therefore improving and developing the services for immigrants are very essential. In addition, there has not been much research done concerning disabled Somalis therefore the topic is in need of more research. Moreover, it is good to take into account that the conception and definition of child's disabilities is largely culture dependent (Helander 1993). Person's cultural background will determine the attitudes towards disability. In addition, the responsibility of disabled person's care and assistant is understood differently in different cultures. (Mölsä 2012, 60.)

The main aim of this study, and the specified research questions arose from the *Tukikeskus Hilma- the Support Centre for immigrant Persons with Disabilities* (Finnish Disability Forum). Hilma wished to get more information on Somali parents' experiences and views about the health care and rehabilitation services for their disabled children in Finland (appendix 9). In addition, what kind of improvements could be done for the disabled child's health care and rehabilitation services from Somali parents' point of views? The views concerning disability in the Somali culture, and how the health care professionals have taken the cultural issues into account are also investigated. The research data is collected by Somali parents' individual interviews with the help of an interpreter. The research subject is very relevant, and the results will be useful principally for Tukikeskus Hilma organization and the whole health care and rehabilitation sector's needs.

## 2 Somalis in Finland

The first regular contacts between Finns and Somalis started in the 1980s, during the instability and civil war in Somalia. In the beginning of 1980 the contacts were mostly related to development cooperation. (Mubarak et al. 2015, 20-30.) Finland targeted a significant proportion of its development assistance to health care, tuberculosis and blood bank projects in Somalia (Finland-Somalia Association 2016). However, the nature of Finnish and Somali cooperation changed when the war in Somalia began in the beginning of 1990s (Mubarak et al. 2015, 20). Somalia entered into complete chaos and civil war in early the 1990s when the country's president Siad Barre was displaced from power (Abdulahi 2007). More than a million Somalis escaped the civil war into neighbour countries, and even further into other countries and continents. Since then the situation in Somalia has been unstable and uncertain. (Mubarak et al. 2015, 27-56.) As the country's instability persists a steady stream of Somali refugees continues to come to Finland (Pentikäinen 2005, 133-135).

Somalia's situation has calmed down a little, but a functioning administration is still missing in the country (Hautaniemi 2004, 44-46). The first Somalis, who escaped Somalia's unstable situation, came to Finland already in the 1980s (Aallas 1991). A bigger group of Somali refugees, who escaped the civil war, arrived in Finland in the beginning of the 1990s (Abdulkarim 2016). Somalis were the first large group of refugees in Finland (Pentikäinen 2005, 121). By the end of the year 1990, approximately 1400 Somalis waited for an asylum decision from Finland (Aallas 1991). During the years 1992-2000, Finland received 5 817 Somali asylum seekers. Few of them were granted asylum status, but many were granted a residence permit for humanitarian reasons. (Hassinen-Ali-Azzani 2002, 70.)

The first Somalis reported to have come to Finland by accident. Finland was supposed to be a transit country to better-known countries such as Sweden, Norway, Denmark, Britain, the United States, and Canada. (Mubarak et al. 2015, 34.) The first Somalis who arrived in Finland were mostly men (Forsander 2002, 134). When the residence permits were granted, many wanted to bring their families as well (Mubarak et al. 2015, 49). Thus, the first Somali women and children came to Finland through the family reunification process (Tiilikainen 2003, 52). Family reunification was the highest between the years 2009-2011. During this time the number of Somali citizens increased significantly in Finland. The spectacular growth is explained by the family reunification, and also by the Somali families' big size. (Mubarak et al. 2015, 49-82.)

Somalis in Finland are a very heterogeneous group; most of them are from southern Somalia, and only a fifth of them are from the northern parts of Somalia (Hautaniemi 2004, 45-47). The group of Somalis who arrived through family reunification had a different profile than the first who arrived. The first Somalis were wealthy and educated compared to those who arrived later. The others were often poorer and less educated, because of the instability and lack of governance control in Somalia. These people have lived a long time in the middle of the war and political conflicts, which has affected them in many different ways. (Mubarak et al. 2015, 49-68.) Therefore, there is much variation between the Finnish Somalis from well educated to completely illiterate. However, the majority are in between these two extremes. (Alitolppa-Niitamo & Ali 2001, 134.)

As the Somali families started to settle down in Finland in the 1990s, the first Somali generation emerged (Tiilikainen 2003). However, building life in Finland has been very slow and challenging for many Somalis. Integration into a new society may be problematic. Many Somalis have encountered various difficulties when trying to adapt to Finland. (Pentikäinen 2005, 237-238.) Some of the Somalis who arrived to Finland in the 1980s are still residing in Finland, and are intending to stay but some are waiting for access to get back to their home country (Mubarak et al. 2015, 27-56).

A notably large portion of Somalis lives in southern Finland (Tiilikainen et al. 2014, 26). Many Somalis reside in the capital region, because the larger Somali community there offers better chances of creating and maintaining social contacts (Tiilikainen 1999, 59). In the capital region it is easier to get jobs and education as well. Also religious activities like Koran schools are more prevalent in the bigger cities. (Mubarak et al. 2015, 165.) According to Statistic Finland (2015), there were 13 485 Somali speakers in Uusimaa region at the end of the year 2015 (Statistic Finland 2015).

Even though there have been Somalis in Finland for more than 20 years, many of them still consider themselves only Somalis and not Finnish. Most consider “Finnish” as a separate community in relation to themselves. Nevertheless, Somalis have differing experiences about their relations with the majority population. Contributing factors are for example language skills, age, the year of arrival in Finland, and whether the person was born in Finland. All of these factors affect the connections with the majority of the population. The majority of Somalis’ friends are from the same culture. However, Somalis belonging to the new Somali generation have more Finnish acquaintances and friends. Younger Somalis have friends from schools, but some of the friendships end during the teenage years because of different interests. (Mubarak et al. 2015, 190-220.) Some Somalis have had very limited contact with the Finnish people, and the contacts have mainly related to meetings with various authorities (Tiilikainen 2003). These are mostly elderly Somalis whose language skills are poor. According to an Immigrant Survey (2013), Somalis would like to know more people from the Finnish general population (Work and the Economy 2013, 71).

The Finnish Somali population has been very active at founding non-profit organizations. There are over 100 registered Somali associations in Finland, and about half of them are in operation. Associations promote cooperation between Finns and Somalis in various means, and inform the authorities about cultural issues. (Pirkkalainen 2013.) The most well known Non-Governmental Organizations are for instance: Suomi-Somalia Seura, Somaliliitto and Suomen Somalia-verkosto.

## 2.1 Somali culture

Somalia is located in the Horn of Africa, next to the Gulf of Aden and the Indian Ocean. Neighbouring countries of Somalia are Ethiopia, Kenya and Djibouti. (WHO 2015.) Somalia gained independence from British and Italian colonial rule in 1960 (Hautaniemi 2004, 47). Most of the Somalia's terrain is dry plain region. The climate is warm, and rain and drought periods are irregular. Deforestation and over-grazing are serious environmental problems. Also, heavy rains and violent floods pose challenges to the locals' life. The lack of clean drinking water causes widespread health problems. (United Nations 2015.) The country has had many problems during its independency; wars with Kenya and Ethiopia as well as famine, and economic difficulties have existed in the country at all times (Tiilikainen 2003, 26-29).

According to the World Health Organization (2015), there were 10 787 000 people in Somalia in the year 2015 (WHO 2015). The world's population growth is focused in certain continents and countries, and one of them is Somalia. Somalia's population is increasing constantly. (Yle 2015.) The main language spoken in Somalia is the Somali language, which is divided into many dialects. The language has many loan words mainly from the Italian, English and Arabic languages. The Arabic language is spoken mainly in religious contexts. (Carvalho et al. 1999, 18.) Somali culture has a very strong tradition of oral expression. Most of the Somalis listen to spoken language rather than read, and some are still illiterate also in Finland (Alitolppa-Niitamo & Ali 2001, 137-140.)

The Somali nation is mainly coherent. However, the nation is divided into different clans and sub-clans. A clan membership runs in a family and is transmitted from father to children. Clans are comparable to a broad network of a family. Through the clan, the individual's identity, responsibilities, sense of justice, and social status are determined. The purpose of the clan system is to provide social, economical, political and legal security to its members. (Alitolppa-Niitanen & Ali 2001, 136-137.) Somalis' names emphasize the clan membership; the first name is their own first name, the second name is the father's first name, and the third name is the great-grandfather's name (Salo-Lee et al. 1996, 6-7).

The country is divided into separate informal parts and thus establishing a centralized government and management has been a challenge (Hautaniemi 2004, 44-46.) The cultural tradition is nomadism, but also other African traditions affect the Somalis' daily life and habits. The majority of Somalis live in rural areas and get their living from livestock (Abdulkarim 2016). This pastoral lifestyle favours families to form clans that then wield political power. Somalia's major political challenge is the incorporation of clans into a national political system. (Pentikäinen 2005, 284.)

Somali culture has been influenced by various events in history and the culture has strong features and customs. Somali culture is communal by its nature and the individual's well being is always based on the community's well being. The needs and priorities of the community are more important than the needs of the individual's. (Alitolppa-Niitamo & Ali 2001, 137-140.) Also, respectful behaviour is an essential part of the culture, especially towards older people (Abdulkarim 2016).

Most of all, Islam plays a major role in the Somali culture (Abdulkarim 2016: Mölsä & Tiilikainen 2007). People belonging to Islam are called Muslims, and Muslims believe in Allah-God. Most of the Somalis are Sunni Muslims and practise Islam regularly. (Akar & Tiilikainen 2009, 14: Mubarak et al. 2015, 132.) In Somali culture, many customs, traditions, attitudes, and gender roles rely on Islamic cultural heritage, and are therefore very important for the culture (Carvalho 1999, 18).

Besides Islam typical outlines for the Somali culture are also for example big families, gender based family roles, dietary habits and women's clothing (Carvalho 1999, 18). Many Somali women use the skirt and scarf proudly; it is part of being a good Muslim and it enhances social cohesion. However, the use of the veil or scarf varies among Somalis, and it is a personal interpretation of the religion's instructions. (Mubarak et al. 2015, 116-118.) There are also certain eating habits and norms in Islamic culture. In general, Muslims do not eat pork or blood products. Alcohol is also prohibited. (Räty 2002, 74.) Even today, most customs and habits appear strong in the culture (Mölsä & Tiilikainen 2007). According to Kinnunen and Puuronen (2006), the minority communities' awareness of their cultural habits and norms are usually emphasized (Kinnunen & Puuronen 2006, 112-115)

### 2.1.1 Islam

Islam came to Somalia through Arab traders in the 900s (Tiilikainen 2003, 35-38). The religion spread throughout Mogadishu into the whole country (Dumper et al. 2006, 252). By the beginning of the 1400th, Islam was the main religion in Somalia (Lewis 2008, 3). Islam came to Europe already in the 700's, and Finland has had Muslims since the early 1800s (Akar & Tiilikainen 2009, 11-12).

Muslims believe that Allah is the only God, and Muhammad is His last Prophet (Atabek 2004: Copeland 2002). The main Muslim belief is that Allah is the creator of all existence and His will is supreme (Yahya 2003). Islam's holy book is the Koran, and Muslims consider the Koran’s words to be words of God. The Koran emphasises the ideology that Islam is Muslims’ everyday religion, and it provides the base for the Muslims’ law. However, the Koran can be interpreted in different ways depending on the reader. On the other hand there are some parts, which do not allow any interpretations, such as the family rules and daily rituals. (Alitolppa-Niitamo et al. 2005, 97.)

Islam consists of five pillars, which Muslims must follow. These pillars are confession to Allah God, praying five times a day, giving alms to the poor, fasting during the Ramadan month and the pilgrimage to the holy place of Mecca. (Hassinen-Ali-Azzani 2002, 140.) The praying moments pace the Muslims’ day; they pray in the morning, noon, afternoon, evening, and early night. The most important praying time is Friday noon. Prayers can be carried out anywhere, preferably on a mat, however the best place is in a Mosque. In Finland, obeying this praying rhythm is challenging for example, at school or workplaces. (Mubarak et al. 2015, 134-136.)

Islam also includes fasting, which takes place in the holy Ramadan month. During Ramadan all Muslims around the world fast for thirty days. Fasting time is from sunrise to sunset, and during that time it is forbidden to eat or drink. The Ramadan month is the time to focus on spirituality and reading the Koran. The fasting is meant for all healthy adults. Some people are exempt from fasting; children under 15 years, the sick ones, weak elderlies, pregnant and breastfeeding women. In spite of the exemption, many pregnant women want to implement the fast at the same time with the community. (Hassinen-Ali-Azzani 2002, 120-121.) One of the most important celebrations for Muslims is *Eid*- celebration. *Eid al adha* is like Finnish Christmas, which is celebrated after Ramadan month. (Mubarak et al. 2015, 134-169.)

Islam is a way of life and it is visible in all the different aspects of Muslims’ lives (Abdulkarim 2016.) It means that Islam, and other cultural life cannot be separated (Kouros & Villa 2004, 250). For many Somalis, the religion is so interwoven to everyday life and is such a big part of their identity that they find it difficult to explain what Islam means to them (Mubarak et al. 2015, 131-132). Islam is a natural part of everyday life for many Somalis, and therefore an important source of a sense of security. By practising the religion, one gets appreciation from others. (Mattsson et al. 2009, 284-288: Ahlström & Wallin 2010, 360.) On the other hand, religiousness may also bring pressure and social control. For many Somalis, the identity of the Islam is even more important than the feeling of belonging to an ethnic group (Alitolppa-Niitamo & Ali 2001, 137-140).

Islam has a central role also in the life of the Finnish Somalis. However, the importance of religion has decreased within some Somali groups. (Tiilikainen 2003, 135-137.) In the year 2012, there were about 60 000 Muslims in Finland, and the largest group among the Muslims were Somalis (Martikainen et al. 2008, 73): as high as 99 per cent of Somalis in Finland report Islam as their main religion (Castaneda et al. 2012, 46). Among the Somalis the religion is practiced in very different ways. Some are very strict with the religious norms and some are so-called habitual Muslims. (Mubarak et al. 2015, 132.) It is essential to take into account that every Somali and Muslim is an individual, and the way they practise the religion varies a lot between the families (Alitolppa- Niitamo et al. 2005, 96).

### 2.1.2 Importance of the family

Every Somali belongs to a big and multi-level relative network (Tiilikainen 2003, 29). Traditionally, Muslim perception is wider than the western perception of the family. The family consists of parents and children, grandparents, cousins, relatives, friends, friends' children, and sometimes neighbours etc. The family unit has no clear boundaries, and children can also be non-biologic. (Akar & Tiilikainen 2009, 14-15.) Parental respect is highly valued in the Somali culture (Mubarak et al. 2015, 110-124). Old age brings authority; grandparents and elderly people are greatly honoured in Muslim families (Carvalho 1999, 18).

The importance of the family stems from Somalia's clan system (Pentikäinen 2005, 283-284). In Somali culture, family relationships are the key elements of social, economic, and political life (Tiilikainen 2003, 29). The large family is individual's social security and a network from where to get help in all life situations (Hill et al. 2012, 75). The family stick together also economically. Somalis living in Finland send remittances to their friends and relatives in Somalia. According to United Nations assessments (2013), the amounts are larger than the amounts of international aid and other investment (Hammond et al. 2011). The family living around the world is cared, and the property shall be distributed among the family and relatives. Some Somalis also support unknown Somalis financially. Also, Islam obliges Muslims giving alms to those in need. (Mubarak et al. 2015, 265.)

Big families are important, and having many children is essential for Muslims. It is considered that children are a gift from the God, Allah. Children, especially boys, will continue and strengthen the father's lineage. However, girls are also welcomed into the Muslim families. In addition, the existence of children is important for the parents' security. Children's responsibility is to take care of the elderly parents. (Akar & Tiilikainen, 2009, 15.) In Somali culture it is common for children to become independent early. Brothers' task is to take care of their sisters and older sisters take care of the younger siblings. (Mubarak et al. 2015.) The principles of raising children include some physical punishment, which might cause shun by the Finnish health care staff (Hassinen-Ali-Azzani 2002, 179-180).

On average, Somali mothers get their first child at a younger age than Finnish women. Because of this, the Finnish Somali’s age structure is much younger compared to the general population. (Mubarak, et al. 2015, 155-156.) Women's education and employment may change the situation in the future. Even though Somalis usually have big families, the number of family members has decreased in Finland. Nowadays, the average family size of the Somali family living in Finland is statistically four children, when in the whole country’s it is 2,4 children. (Statistics Finland 2013.) Today, many large Somali families are scattered around different countries due to people’s mobility, wars and refugee situations. Despite this, the geographical cross-border family ties have remained important to many Muslim families. On the other hand, some Somalis do not have any relatives in Finland as their only relatives live in Somalia. (Mubarak et al. 2015, 279.)

Somalis usually get married at a young age, and after the wedding ceremony the couple can move in together (Mubarak et al. 2015, 169). In marriage a man and a woman are equal and full members of the community. The majority of Somalis marry a person from the same cultural background. Their families arrange some of the marriages. (Latomaa et al. 2013, 167.) Marriages in Somali society are often fragile and uncertain, partly because of polygamy, but also because of women's division of loyalty between two families (Marjeta 2001, 30). According to Koran, Muslim men can have the right to be married with four women at the same time (Akar & Tiilikainen, 2009. 14-15). Polygamy is not allowed in Finland and people are only allowed to have one spouse by law. This is very different in the Somali culture, as in Islam it is accepted for men to have a second wife or wives. However, many Somali women do not accept polygamy. (Tiilikainen 2013, 176.) Reasons for polygamy are for example, infertility and a limited number of born boys. Polygamy is important for some Somali men because they want to strengthen their families through boys and therefore they want to get as many boys as possible. (Marjeta 2001, 30.) Many women have also been widowed and single parents because of the wars and separation through geographical distance (Tiilikainen 1999, 22-23).

### 2.1.3 Gender roles

In the traditional and partly old-fashioned Somali culture men and women have different roles in the society. Roles between the sexes have a great importance in Somali tradition. (Skott & Svenberg 2009, 284.) Some of the gender role models are based on Islam (Mubarak et al. 2015, 110). Traditionally, Somali culture is patriarchal and male dominated (Carvalho et al. 1999, 18: Tiilikainen 2003). Patriarchal ideologies, habits and customs are clearly visible in the culture, economics and politics. In a patriarchal culture women are inferior to men. Furthermore, in the Somali culture women are considered intellectually weaker than men. (Tiilikainen 1999, 21.) Traditionally, a Somali woman cannot show their feelings, as a woman should be and to act as "a tireless machine" (Tiilikainen 2003). The man is the head of the family and woman must accept the authority of her husband (Mahamoud et al. 2002, 22-25.)

The Somali culture’s gender roles are divided into very traditional roles of men and women. Roughly put, the home- and housework as well as childcare belong to the women and family girls. Women’s life consists of only the home and surrounding neighbourhood. Parenting is mainly the responsibility of the mother, but it is also important for fathers. (Mubarak et al. 2015, 110-113: Tiilikainen 2013, 175-177.) Thus, the children have a strong emotional bond with their mothers. However, the whole Somali family and community are responsible for raising the children. (Alitolppa-Niitamo & Ali, 2001, 137-140.) In divorce situations, the children usually stay with the mother (Skott & Svenberg 2009, 284). Islamic law provides different rights for men and women regarding divorce situations (Mubarak et al. 2015, 170).

Somali men’s roles are mainly to be the family’s breadwinner and guardian. The man takes care of the family’s economy and decisions. The man is also responsible for the maintenance, protection, and the family’s overall wellbeing. (Mahamoud et al. 2002, 24.) Men's position in society determines the whole family’s status (Tiilikainen 2003, 29-35). Furthermore, men’s success and masculinity is measured by his success (Tiilikainen 1999, 21). According to Islam, even though the gender roles are distinct the purpose is to establish symmetry between the respective rights and obligations of men and women. Despite the patriarchal view, women's work is also highly valued. (Mahamoud et al. 2002, 21-24.)

Children at an early age are already taught the different worlds of men and women, and given gender-based tasks. Growing up in a large family teaches childcare to Somali women. For example the family’s women teach household tasks to the girls. (Hassinen-Ali-Azzani 2002, 179-180.) Generally speaking, both girls’ and boys’ education is valued in the Somali culture, although in many Islamic countries, girls' education level is lower than boys’ (Akar & Tiilikainen 2009, 17.) On the other hand, Somali girls born in Finland have gone ahead of boys in education (Kilpi 2010).

### 2.1.4 Cultural changes

According to Mubarak et al. (2015), the perception of being a man or a woman is different compared to Somalis born in Finland and their parents who were born in Somalia. The family perceptions may differ between the young and the elderly Somali families. Somalis who have been born in Finland or who have arrived to Finland at a young age are multi-cultural in many ways. (Mubarak et al. 2015, 112-113.) In their current home country, the immigrant children are influenced by the surrounding society. They will learn new habits and customs from the main population. (Aden et al. 2000, 114.) In turn, those Somalis who came to Finland at an older age are more committed to Somalia's traditional culture (Mubarak et al. 2015. 112-146.)

The characteristics of the conservative and patriarchal Somali family model are very different compared to the western style of equal and individualistic family model. Being an immigrant in a different society and culture puts also the gender roles on trial. Therefore, the gender roles are constantly changing in Somali communities as well. (Skott & Svenberg 2009, 284.) Clash of two totally different cultures causes conflicts inside the families. Pressure comes from two different directions, Somali and Finnish culture. (Aden et al. 2000, 110-114.) Changing role models have raised tensions but also possibilities within the Somali families (Tiilikainen 2003, 34).

Nowadays, Somali families' position has changed as a result of dispersed living. In Finland, the government takes care of many tasks, which previously were taken care by the Somali family itself. Family's welfare has become dependent on the government's welfare services, such as education, day care and health care, which have previously been on the families' responsibility in Somalia. (Tiilikainen 2003, 173.) According to Aden et al. (2000), both genders find it difficult to combine traditional Somali tradition to their present life in a western country (Aden et al. 2000, 110-114).

In Finland, women share an equal status with men. Before, the Somali man was the head of the family and was respected in his role. These changes in the perceptions have led Somali women to demand more authority. This kind of situation may cause harm, if the Somali man wants to maintain the traditional gender roles. (Skott & Svenberg 2009, 284.) Also, difficulties finding an employment have brought problems to a man's value in Somali society (Toivanen et al. 2013). In Somalia men have often had respected jobs and more money (Tiilikainen 2013, 173). The Finnish labour situation, poor language skills and the lack of education are barriers for getting a job (Toivanen et al. 2013.) Several Somali men have lost their authorities as breadwinners, because most of the Somalis live on the government welfare payments (Tiilikainen 2013, 174).

Concerning unemployment among Somalis who did not have a Finnish citizenship. The Unemployment rate among Somalis in Finland without Finnish citizenship was 65.7 per cent in 2012 (Statistics Finland 2012). Citizenship could for instance, help the person to engage more into the Finnish society, and contribute in the fields of education and labour (Pentikäinen 2005, 128). The high unemployment rate affects the men's role in the family. The men cannot carry out their traditional role as men and are obliged to take part in the household tasks, which may cause humiliation to the men. (Mubarak et al. 2015, 124.) This leads to the situation were women do not need their man anymore and are able to manage on their own. Therefore, many men may feel that they are useless, and do not know what to do. (Tiilikainen 2013, 174-177.)

Somali men may have gone through more changes than women in adapting to the Finnish society. Women have been able to hold their household tasks, but also been offered new opportunities. (Tiilikainen 2003, 174.) However, Somali women have had great challenges when trying to fit into the image and status of women and women's expectations by the western society (Abdukarim 2013). Lack of knowledge of Finnish language makes the women dependent on their men in a new way (Tiilikainen 2003, 174).

While the traditional division of gender roles still exists in Somali culture, Somali men are forced to participate in household tasks and childcare more, which would have been unheard of in Somalia (Tiilikainen 2003, 174). Although in some Somali families household tasks are divided between the wife and the husband (Mubarak et al. 2015, 112-124), the new situation and particularly the new expectations for men may lead to disputes between spouses (Tiilikainen 2003, 175). As a result, changing gender roles and divisions of the roles have increased the number of divorces (Skott & Svenberg 2009, 284).

Among Somalis, divorces are more common than in other minority groups in Finland (Mubarak et al. 2015, 156-157). The woman is usually the one who files for divorce, because in a western society she can manage without her man's financial support (Skott & Svenberg 2009, 284.) In most cases, the stated reason for divorce is that men are not able to redeem their expectations, and in Finland Somali women can economically raise the children by themselves (Mubarak et al. 2015, 157). However, sometimes also the men want a divorce due to the fact that women can manage on their own and are too independent (Skott & Svenberg 2009, 284). 42 per cent of Somali women indicated that they were single parents (Säävälä 2013, 116). Single parenthood is partly affected by polygamy and partly it is due to the fact that the man lives abroad (Mubarak et al. 2015, 156-157).

Among the Finnish Somalis, Finnish language is slowly becoming a more integral part of everyday life, although Somalis rather speak their mother tongue. (Perhoniemi 2006.) Knowing their own language and the use of it is seen as a very important way to keep up their culture. (Perhoniemi 2006.) Today, knowing English is essential as well. Arabic is studied for Koran school. Many of the new generation Somalis are multilingual and they mix Somali, Finnish and English together. (Mubarak et al. 2015, 203-211.)

According to THL report (2012), every four in a thousand Somalis in Finland announced that they have not attended comprehensive school. Every fourth has some second-degree education and every fourth was still a student. The Somali women were the least educated group among the Finnish Somalis; one-third had not been to primary school and a third reported to be housewives. Every sixth Somali woman writes and reads poorly, or not at all. (Castaneda et al. 2012, 54-55.) Among Somali women, there are many who do not have any education (Toivainen et al. 2013).

According to Pentikäinen’s study (2005), about Somali refugees, a number of Somalis experience that life in Finland is slightly incomplete. Many have been more active and felt being more useful in their country of origin and in Finland many are unemployed. (Pentikäinen 2005.) Those Finnish Somalis, who are working, are mostly employed at the healthcare-, construction- and transport sectors (Mubarak et al. 2015, 237-239). Occupations are divided clearly between men and women. The most popular sector for women is health care and for men is the transport sector. (Statistics Finland 2012.) By far the most popular profession among the Somalis is a doctor (Mubarak et al. 2015, 237.)

## 2.2 Health care in Somalia

According to the World Health Organization (2004), public health care services are lacking in Somalia. Access to health care services is very low for many Somalis especially nomads in the country’s rural areas. There are no hospitals in every city. (WHO 2004.) The access to health care services is very weak especially for women and girls. In Somalia women and girls acquire only a little health- and illness care. The traditional way of thinking is that women’s health and wellbeing is not economically worthwhile. (Alitolppa-Niitamo et al. 2005, 96.)

Furthermore, mental health care is not understood in Somalia and the services barely exist at all. There are not even words for psychology or mental life in the Somali language. (Alitolppa-Niitamo et al. 2005, 96.) Many of the trained doctors and nurses work at the private sector. Authorities do not control the quality, storage or distribution of medicinal products in Somalia. Due to the lack of the health care services, the traditional treatment methods are common in Somalia. (Mölsä & Tiilikainen 2007, 452.)

In Somalia, health care is often combining different forms of treatment. The disease can be treated traditionally and by using western health care. (Alitolppa-Niitamo et al. 2005, 96.) According to Slikkerveer (1990), in traditional Somali health care two treatment methods can be separated. Firstly, health treatments based on supernatural beliefs like God and different spirits and secondly, health treatments based on herbal medicine. Various health treatments can be used simultaneously and combined with western medical treatment. (Slikkerveer 1990.) Especially in rural areas traditional folk medicine and traditional healers are highly appreciated. The traditional folk medicine combines magic, prayers and herbal treatments. (Hassinen-Ali-Azzani 2002, 35.)

The given health care varies depending on the type of the healer, and the diagnosis given to the patient (Mölsä & Tiilikainen 2007, 454). The presumed cause of the disease is often the guiding factor of choosing the treatment. Treatment often begins with self-medication and home care. Treatment decisions are usually done by a treatment group, which involves family members, relatives, friends, traditional healers, and sometimes a pharmacist, doctor and a nurse. The patient is usually not involved in the treatment plans. (Alitoplla-Niitamo et al. 2005, 96.)

In Somalia and in the Horn of Africa region female circumcision has long traditions. It is estimated that 98 per cent of Somali women and girls have undergone some form of genital mutilation. (World Bank 2004, 5.) Still today girls' circumcision is practiced widely in Somali culture (Hassinen-Ali-Azzani 2002, 35). According to National Institute for Health and Welfare research (2012), 70 per cent of Somali women living in Finland were circumcised. Somalis were usually circumcised before coming to Finland since women circumcision is illegal in Finland. (Castaneda et al. 2012.) According to the Finnish Criminal Law, female circumcision, in its all forms is defined as a criminal offense (Ministry of Justice 1889). Also, exporting girls abroad to be circumcised is forbidden. Nevertheless, it is still possible that girls' circumcision exists somewhere in Finland among immigrants. (Akar & Tiilikainen 2004, 19.)

Female circumcision is not taught in Koran and it is not part of Islam. However, in the Islamic world interpretations of Koran that defend female circumcision can be found, especially concerning the less severe forms of the circumcision. (Akar & Tiilikainen 2004, 18-19.) Female circumcision is an old tradition in Somalia, which is associated with the transition of the girls becoming women and obligations relating to that (Hassinen-Ali-Azzani 2002, 35). In Somalia, circumcision is thought for example to protect girls from promiscuity and premarital pregnancies. Generally, circumcision has been a prerequisite for marriage. In addition, girls’ circumcision is justified with reasons relating to aesthetics, purity and sexuality. (Akar & Tiilikainen 2004, 18-19.)

However, mutilation can cause serious immediate complications and later health problems (Hassinen-Ali-Azzani 2002, 52). Today, people's attitudes towards female circumcision are changing. Girls' circumcision is not considered to be something that everyone must go through. Changes in attitudes have been influenced by many factors such as increased education and awareness. (Mölsä 2004, 22.)

Also, the circumcision of boys has a long tradition in Islamic culture. Male circumcision is not obligatory for boys and men living in an Islamic community. Although according to some interpretations, a man is not considered as a plenipotentiary if he has not gone through the circumcision. (Akar & Tiilikainen 2004, 16-17.) Circumcision of boys is not a crime in Finland, however it is a controversial issue between impunity and practice of religion. Circumcisions done by without a medical purpose are against the Finnish medical guidelines. (Saarni et al. 2013, 100.)

In Somali culture, health is seen as the basis of life, because without health there is nothing. Health and wellbeing are understood as all encompassing. With the help of good health, it is possible to manage the obligations of life. Health includes wellbeing, happiness, and balance between humans and nature. (Alitolppa-Niitamo et al. 2005, 96.) For Somalis, good health includes for example, good relationships, respect from others, and safe place to live (Ahlsröm & Wallin 2010, 361). Generally, the knowledge of safety and well being of relatives left in the country of origin and children's success were also important factors which affect an immigrant's health and welfare (Malin & Gissler 2006).

In Somali culture mental and physical characteristics are strongly interlinked. The difficulties and illnesses are physical signs of the body's imbalance. (Alitolppa-Niitamo et al. 2005, 96.) According to Elmi (1999), in Somali culture, the person is either sick or in good health, and there is no middle ground situation between these two state of affairs (Elmi 1999). Somalis consider that lack of social relationships and isolation cause sickness to people (Ahlsröm & Wallin 2010, 361: Brand et al. 2010, 355.) According to Islamic traditions, also the spirits like *Jinns,* witchcraft, and *the evil eye* can cause diseases for people (Perho 1995).

When someone is sick, the whole family takes care of the patient. Visiting the sick person is a Muslim's essential duty. Also, seeing the family and friends will relieve the sick person's diseases. (Tiilikainen 2013, 225.) Somalis often spend time in the company of friends and family when being sick, because companionship will enhance the healing. Friends and relatives read Koran for the sick one and that is also considered to release the pain and sicknesses (Finnström & Söderhamn 2006, 422-424). On the other hand, it can be easy to hide personal problems when living in a big community with other people. According to Brand et al. (2010), in communities where everybody knows each other, sicknesses or other family problems are easily kept hidden, because the hear of other people's reactions (Brand et al. 2010, 358).

In Somali culture, health and sicknesses are seen as aspects, which come directly from God (Ahlström & Wallin 2010, 360). According to Elmi (1999) "illness and healing occur only by the will of God" (Elmi 1999, 5). Health is not in people's own hands, it is the gift of Allah. Allah does not impose the disease for humans on purpose, but everything is considered to have a higher meaning. (Alitolppa-Niitamo et al. 2005, 96.) According to Tiilikainen (2003), Muslims treat illnesses with patience and accept the diseases. They are not angry with the God, and not hopeless because they count on God's support. (Tiilikainen 2003.)

Sickness and pain should be accepted as the will of Allah, and be carried with dignity. Because the disease comes from Allah, the God also decides what will happen. Sicknesses should not be questioned; otherwise God might punish the questioner. Also, to become distraught due to an illness is seen ungrateful towards Allah, and shows lack of the person's religious faith. Somalis believe their lives belong to Allah, and therefore showing gratitude towards Allah in every aspect of life is essential. (Ahlström & Wallin 2010, 360; Finnström& Söderhamn 2006, 422) According to the Koran, Muslims get what they deserve and what is predestined for them. Therefore, the diseases can be seen as punishments or rewards. Koran lists rules and guidelines, which serve as the basis for a good health; healthy lifestyle and good manners are conditions for good health. (Alitolppa-Niitamo et al. 2005, 96-97.)

### 2.2.1 Somali health care and western medicine

Health care in Somalia differs a lot from the western health care (Brad et al. 2010). According to Islam, God has all power and strength also on health matters. Humans must accept the will of God. Also, good social relationships protect health. (Tiilikainen 2003, 214.) The belief in Allah is stronger than the trust for the Western science and technology. Somalis believe that, despite the medicine, the result is always on the hands of God. (Aden et al. 2010, 108: Hill et al. 2012, 75-76.)

In Somali culture the health care rely more on intuition, family's opinions, and Somali traditions than in Western-style health care (Doescher et al. 2010, 11). Some Somalis have a lack of confidence towards western medicine (Hill et al. 2012, 75-79). If the health situation of Somalis living in Finland worsens dramatically, they may travel back to Somalia, since it is believed that they will receive the correct care and treatment there (Mölsä & Tiilikainen 2007, 454). On the other hand, some Somalis who were sick felt themselves safe in Finland because of the security and access to medical care (Ahlström 2010, 360). However, compared to other minority groups Somali men have the greatest confidence in the Finnish social and health care (Castaneda et al. 2012).

According to previous studies, Somalis questioned health care provider's recommendations when they differed from their families' opinion (Hill et al. 2012, 75). Mental health care problems are not understood in Somali culture (Alitolppa-Niitamo et al. 2005, 96). In particular, the treatment of mental problems is very different and, for example anti-depressant medicines will not be accepted (Mölsä & Tiilikainen 2007, 454). Differing opinions about mental health care might cause problems and prevent Somalis from seeking psychiatric care. Immigrants have a relatively greater risk for mental health disorders and especially traumatic disorders and depressions are common among immigrants. (Lindström et al. 2009.)

According to Brandt et al. (2010), the care and treatment are more straightforward in Somali culture compared to western medicine. In western medicine it is important to find out the reasons for the symptoms, while in Somali culture the symptoms are treated. There are various reasons why Somalis sometimes distrust the western health care system, for instance: difficult ethology of various types of examinations, the long waiting time for hearing the results and constantly changing attending doctors. More importantly, the importance of preventive health care is not understood among many Somalis. (Brand et al. 2010, 356.)

According to Hill et al. (2012) and Carroll et al. (2007), health care staff's gender has a great importance in Somali culture. A large proportion of the Somali women thought that being in contact and touched physically by male healthcare staff was forbidden. The Somali women felt that talking to a female healthcare professional was easier and more straightforward. Male health care staffs were only allowed to be used in emergency situations. Only a small minority of Somali women consider that the gender of the health care worker does not matter. (Hill et al. 2012, 78: Carroll et al. 2007, 341.)

Changing gender roles are also visible in the health care sector. Traditionally in Somali culture, men have not participated in childbirth. Nowadays, Somali immigrant women lack sufficient support network because some of the family members are living in different countries. Also, language barriers cause difficulties in health care. Because women lack language skills, they have become more dependent on men. Women feel that they have lost something of their own, when men have started to participate more in childbirth and men on the other hand feel they need to take more responsibility in a situation that is not natural to them. (Hill et al. 2012, 76: Aden et al. 2000, 114.)

### 2.2.2 Somali customer in Finnish health care

Meeting and treating patients from other countries and cultures constitute challenges also in health care. Somalis' perceptions of illness and health care differ a lot from Western medicine. (Lewis 1998: Carroll 2004.) However, Somalis highly appreciate Finnish health care services and are major health care service users, particularly in the metropolitan area (Mölsä & Tiilikainen 2007, 451-453). Therefore, it is important to pay attention to the advice and guidance given to a Somali customer. Also, as a constitutional right (§19), migrants residing permanently in Finland are entitled to the same services and social security as Finnish citizens. However, many immigrants may face prejudice, racism and discrimination when seeking help (Peltola 2005).

It is important to remember that Somalia's healthcare service system is totally different compared to Finland's health care system (Mölsä & Tiilikainen 2007, 452.) The different health care service system in Somalia might cause confusion and complicate the use of services in Finland. The Finnish social, health and rehabilitation services are criticized by their complexity and dispersion and understanding the complex heath care service system can be difficult for many native Finns as well. (Peltola 2005.)

In Finland, Somalis have encountered entirely new aspects in the health care sector; health care technology, minute schedule in appointments, as well as child health care centres and nursing homes for elderlies. Some Somalis might refuse to partake different operations because of fear and misunderstandings. (Mölsä & Tiilikainen 2007, 452.) As Peltola (2005) states, the health care services that are designed for the majority population do not necessarily meet the needs of immigrants (Peltola 2005). According to Silvennoinen (2000), study shows that health care professionals are experienced that Somali immigrants are friendly, polite and humorous people. They were seen as people with a lot of life experience, and who do not easily show their emotions, such as sadness. The study concludes that they do not admit, if they have not understood the care and maintenance instructions or advice. (Silvennoinen 2000.)

Islam provides the basis for how health and sickness are perceived in Somali culture. They strongly believe that health and sickness are in the hands of Allah. There are big differences in how the rules of Islam are interpreted and obeyed. The most important thing with the patient and his or her family is to discuss and negotiate the sick person's health care. Although everyone is different, some general points about the cultural issues are good to keep in mind. (Mölsä & Tiilikainen 2007, 454.)

Obviously, different languages can cause language barriers between Finns and Somalis in health care sector. Most of the elderly Somalis do not speak Finnish. (Mölsä & Tiilikainen 2007, 453.) They have also had very limited contacts with Finnish people (Mubarak et al. 2015, 190- 195). Lack of the language skills can make the use of health care services difficult or even impossible (Peltola 2005). Also, one important aspect is Somali language's strong oral tradition. Somalis use more verbal than written language and some Somalis are still illiterate. In Finland most of the important messages like health care appointments from authorities come by mail, which might cause misunderstandings. It is good to take into account that important messages are always said verbally as well. (Mölsä & Tiilikainen 2007, 453.) On the other hand, poor language skills might cause misunderstanigs also via telephone (Peltola 2005).

Avoiding language barriers and misunderstandings, it is important to use interpreters when needed. The interpreters are most needed in social- and healthcare services. On the other hand, many Somalis feel that talking directly to the professional about their own affairs would be easier than through the interpreter. Using interpreters may give a feeling about insufficiency and one cannot be sure that everything has been translated. Many Somalis prefer to use family members as an interpreter. (Mubarak et al. 2015, 206-208.)

Somalis consider that open discussion, friendship and acceptance are important. Somalis urge Finnish people to be open-minded and curious about Somali culture. (Mubarak et al. 2015, 288-292.) According to Carroll et al. (2007), Somali immigrants appreciate if the health care workers show interest and respect towards their culture (Carroll et al. 2007, 340). Respect can be shown with things, like understanding that a Muslim does not necessarily want to shake hands or even be in the same room together with the opposite sex. Therefore, it is important to make sure that for example, Somali women are able to get a female doctor. (Räty 2002, 74-75.)

The first contacts between the health care worker and a Muslim are important (Mubarak et al. 2015, 190-195). Cultural sensitivity is important and it is good to pay attention to the cultural values, beliefs and behaviours (Stone 2005, 34). Health care professionals must have at least the basic knowledge of the cultural factors concerning health, sicknesses and their usual treatments when dealing with Muslim customers. On the other hand, the immigrant status can sometimes cause problems in the health care service field. The attitudes towards immigrants might still sometimes be negative or sometimes immigrants are understood “too much”, which means that some things are explained by the cultural differences which should not be (Malin & Tiilikainen 2002).

## 2.3 Disability in Somali culture

People coming from different cultures can have very different views about customs, traditions, political views, religious, and perceptions of right and wrong etc. (Liebkind 1994. 21). Moreover, the concept and definition of disability is culture depend (Helander 1993). Perceptions towards disability are always associated with cultural experiences and beliefs about what is a good life, how the disability affects life, and what causes the disability (Leimiö 2012, 46.) According to Mölsä (2012), cultural background will determine the attitudes towards disability for example, how a disabled person is defined, encountered and treated in the society. In addition, the responsibility of disabled person’s care and assistant is understood differently in different cultures. (Mölsä 2012, 60.) Depending on how disability is understood in the person’s culture, determines if the person have disability or not (Ypinazar & Margolis, 2006).

According to Stone (2005), it is important to examine how disability is seen and understood in your own culture, before trying to understand how other cultures understand and define it (Stone 2005, 25). According to Ypinazar and Margolis (2006), several aspects should be considered when discussing disability in various cultures (Ypinazar & Margolis, 2006.) According to Stone (2005), very often the proclivity is taken as facts what we learn from other cultures and stereotype it to everyone who is a member of the group. It is good to take into account that there are many definitions for disability inside and between different cultures and groups. Also, everyone understands disability in a different way and each of us has experiences based on their own unique opinion of what disability is. (Stone 2005, 17-31.)

Among the definition of disability, disabled people's social status, and politics may also differ a lot from other culture's perspectives. According to Urhonen (2012), in Western societies, the prevailing view for disabilities is mostly biophysical, but for example, in many developing countries, disability is explained by paranormal reasons and religious beliefs. (Urhonen 2012, 58-60.) Secondly, English language has wide range of the disability related terms but many languages are lacking the word disability (Stone 2005, 5). Thus, some languages may have a broader term that embraces both illness and disability (Hasnain et al. 2008, 5).

In Finland there are various research concerning disabilities but this might not be the case in other countries. Research has prevented wrong perceptions and beliefs from occurring. The knowledge has made possible that the wrong perceptions and beliefs do not occur. The information has also enabled critical examination and questioning towards taboos and stigmas. (Leimiö 2012, 46.) All people and cultures might not have as much information about the different disabilities for example, diagnosing, care and rehabilitation as we do. Therefore, the expectations among people with different cultures can be unrealistic for example, towards Finnish health care system and disability care. (Vammaisfoorumi.) On the other hand, in many Islam families, the disabled person's functionality is more important than the specific diagnosis for the disability. (Ypinazar & Margolis 2006).

The meaning of religion is significant when examining the different cultural perceptions of disabilities. The religion strongly determines the culture and therefore also the attitudes towards the view about disabilities. In the Christian as well as in Islam, indications have been found that the disability is a person's impairment. What stronger role the religion has in the culture the more the religious ideology affects the disabled person's treatment. Disability is often explained to occur due to the person's own or his relatives' bad acts, which can be one reason for disabled peoples' poor, even cruel treatment. (Urhonen 2012, 58-60.)

On the other hand, in some cultures, a disabled person is special, and he has received a task or a gift from the God. In such cultures, the role of the disabled person in the community is very important. Then, in some religious disability is expected to be cured, and believing into a "miracle healing" is common. Waiting for the "miracle" sets aside the idea that people with disabilities are socially as eligible as others. (Urhonen 2012, 58-60.)

According to the statistics, about 10 per cent of the world's population are disabled, and about 80 per cent of them live in developing countries. Various disabilities in developing countries have not been studied much, because there are more severely everyday problems such as poverty and survival. The attitudes towards persons with disabilities are almost all strongly discriminatory in developing countries. (Teittinen 2006, 100-102.) Also, a person with disability belonging to a minority cultural group sets him to a minority within a minority, and therefore might face a double risk for social exclusion. Especially immigrants with severe disabilities are easily isolated if their needs are not taken into account. (Ministry of Social Affairs and Health 2006: Koskela 2003.)

According to World Health Organization, it is estimated that approximately 10% of Africans have some kind of disability (WHO). However, it is good to remember that there is only limited data from African countries about the actual prevalence of disabilities. (Fujiura, et al. 2005). According to Peters (2003) the amount of disabled children in Africa may increase due to the growing poverty, conflicts, child labour, violence and abuse, as well as HIV/AIDS. (Peters 2003.) There is not a specific health care or financial support system for disabled people in Somalia. Also, there is no pension or insurance system that would support people with disabilities and their families. Therefore, people with disabilities are depending on other people's help, and assistance. They do not have possibilities for an independent life. Traditionally, relatives, mainly women, have been taking care of the people with disabilities in Somalia. Also, education for disabled people has been considered needles in Somalia. (Mölsä 2012, 60.)

Before the civil war time in Somalia, some of the people in urban areas had the opportunity to follow pregnancy and child development in certain clinics, although testing genetic diseases was not possible. However, the situation of disabled people has improved by many ways in Somalia. The citizens have promoted disabled people's situation for example, by establishing disability centres, deaf and blind's schools, as well as providing implement tools. Although the implement tools are available for most of the disabled people cannot afford to buy a wheelchair for instance. (Mölsä 2012, 60-63.)

Conceptions of disability are very different in Somali culture than in western societies' medical view (Pegg 2004, 50). For many Somalis intellectual disability is a taboo, which is not spoken aloud. In particular, Somalis do not want to talk about it openly especially with people outside the close family. Mobility disabilities are accepted more easily than for example, shameful intellectual disabilities. (Mölsä 2012, 60-62.) Although disability is still taboo in some parts of the Muslim culture, small progress has been achieved towards disability rights (Bibbo 2006).

In Somalia disability is thought to be a punishment from the God - It can be a curse for the parents' infidelity or criminal offense. On the other hand, disability can be considered as a blessing or teaching. Intellectual disability is seen as the Allah's will, and therefore it is a blessing. Most Somalis believe that disabilities have natural causes or that they are inherited.

Although heredity is recognized, marriages between close relatives are still common. (Mölsä 2012.) According to Pegg's (2004) research, Somalis may confuse intellectual disability and mental health (Pegg 2004, 50). According to Islam there is a distinction between the person with mental disorder and intellectual disability, but both are found legally incompetent in the Koran. (Morad et al. 2008.)

On the other hand, according to Islam, disability is morally neutral. It is either a blessing or a curse. Disability is accepted as being an inevitable part of the human condition. It is a fact of life, which has to be handled appropriately by the society. In Islam societies, people with intellectual disabilities are obliged to respect and assist others. They should be given an equal life chance as well. Islam does not allow discrimination on the basis of any differences (gender, ethnicity, colour, physical, etc.) (Morad et al. 2008.) Although the causes of disability are explained almost always by hereditary factors in Somali culture, there is a belief for a connection to various beliefs and myths. In Somali culture they strongly believe that for example eating liver can cause difficulties in speaking or delays in speaking for small children. There is also a belief that being in landfill or near can cause a disease, which leads to the disability. It is also a common belief that witchcraft and *the evil eye effect* can cause the disease of which consequence is disability. The child can expose the evil eye if he or she is cared or praised too much. (Mölsä 2012, 60-62.)

In Somali culture, abortion is not allowed because of religious reasons. Abortion is prohibited even though there is evidence that child has some disabilities. Also, Finnish Somalis do not accept abortion even though the pregnant follow-up survives shows the child's disability. Pregnancy will be exported until the end, even in those situations where it is clear that the child will not live long. (Mölsä 2012, 61-63.)

Finland's good health care services give better opportunities for disabled Somalis. Awareness of the various services for the disabled people depends on the family; the time period the family have lived in Finland, education and social networks etc. It is generally considered that the services in Finland are good, and better than in Somalia, but reaching them is difficult and very complex for Somalis. (Mölsä 2016, 63.) Muslims might encounter various barriers and challenges when using the mainstream health care services for their family members with disabilities. Among the many barriers is for example, the multidimensional health care terminology terms such as intellectual disability is culturally sensitive definition (Raghavan et al. 2007).

# 3 Finnish health care

According to the Finnish constitutional law, the government has to ensure the availability of the adequate social and health care services for every Finnish person (The Health Care Law 1326/ 2010). In The Finland Social and Health Ministry has the responsibility to arrange the social and health care services for the citizens. Approximately 440 municipalities across the country are responsible for the distribution of the health care services. The public sector (municipalities) is the biggest health care service provider in Finland. In addition, private companies and organizations provide health care services. (Ministry of Social Affairs and Health 2013, 11.)

Municipalities are responsible for providing necessary health care services for their own territories. Municipalities can produce the services on their own or they may cooperate with neighbouring municipalities and provide the services in cooperation with them. Municipalities can also buy services from other municipalities, organizations or private service providers. (Ministry of Social Affairs and Health 2013, 11.) The legislation defines the main services that municipalities need to provide. However, the municipalities can determine the extent of services, services' content and the way the services are provided. Therefore, there can be differences between the provided services in different municipalities in Finland. The services are largely financed by national municipal tax revenue. Also, the government provides some financial support for all the municipalities. This system ensures that the patient only has to pay a small fee for the health care services. (Kunnat 2015.)

Finland is divided into different health care districts. In Finland there are 20 different health care districts. The health care districts are in charge of providing specialized health care. Children's intellectual disabilities are always diagnosed in specialized health care and disability care or specialized health care is responsible for the treatment. (Kaski 2005.) The specialized health care or disability care provide for example medical rehabilitation and some other special services for intellectually disabled people. Usually, health insurance or the Social insurance Institution covers the fees. (Ministry of Social Affairs and Health 2013, 12.)

Children with special needs who are not diagnosed as intellectually disabled, get the care and other services from the primary health care. The rehabilitation of children with different special needs, such as various therapies, is paid by the municipality taxes and government support. Monitoring their development continues in primary health care if there is no need for special treatments. (Ministry of Social Affairs and Health 2013.)

## 3.1 Disability

According to World Health Organization (WHO), disability is an umbrella term for covering impairments, activity limitations, and participation restrictions (WHO). United Nation’s Convention on the Rights of Persons with Disabilities (CRPD), definition for a disabled person is; *“a person who has long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”* (United Nations 2016)

World Health Organization has published a classification of health and health-related domains: International Classification of Functioning Disability and Health (ICF 2001). ICF defines disability: *“as functioning in multiple life areas. Disability is seen as a result of an interaction between a person and that person's contextual factors, such as environmental factors and personal factors. Disability covers a spectrum of various levels of functioning at body level, person level and societal level. Disability denotes all of the following: impairments in body functions and structure, limitations in activity and restriction in participation.”* (WHO 2001.)

More functional definition than the previous ones is American intellectual disabilities Organization's (AAIDD) definition for intellectual disability. In Finland, more than 90 per cent of people who get services in accordance with the special law also fulfil the obligations of the American intellectual disabilities organization’s criterions (Kaski 2002). According to American Association on Intellectual and Developmental disabilities (AAIDD), there are three major criteria for intellectual disability. Firstly, intellectual functioning has significant limitations. Intellectual functioning includes for example, the mental capacity for learning, reasoning, problem solving, etc. Intellectuality is measured by the IQ test. A person with intellectual disabilities has a below 75 IQ. Secondly, a person with intellectual disabilities has problems in adaptive behaviour. It includes difficulties in everyday social and practical skills like for example, problems in communication, self-care, living at home independently, social skills, work in the community, self-management, health and safety, functional learning abilities, leisure and working in a community. Thirdly, the intellectual disability is discovered before the age of 18. (American Association on Intellectual and Developmental Disabilities 2013.)

According to Finnish association on Intellectual and Developmental Disabilities (2016), there are about 400 000 – 200 000 Finnish people who has some kind of disability. Also, approximately 40 000 people have an intellectual disability. (Kehitysvammaliitto 2016.) The proportion of disabled people therefore varies a lot depending on the used definition (Nikkanen 2010) and the definition for disability varies in different societies and different interpretations (Savtscenhko et al. 2010, 67).

The variability of symptoms and problems among the disabled people varies a lot too. In other words, there is not such thing as a typical disabled person. Different definitions of disability do not exclude or replace other definitions. The purpose of different definitions is usually to serve different purposes. (Savtschenko et al. 2010, 68.) Generally, disabled people represent 10 to 20 per cent of the world's population (Shakespeare et al. 2009.) According to the Ministry of Foreign Affairs in Finland (2016), people with disabilities are the largest minority in the world (Ministry of Foreign Affairs 2016).

### 3.1.1 Intellectual disability

Intellectual disability is a central nervous system's developmental disorder, and it is caused by the central nervous system's dysfunction (Arvio & Aaltonen 2014, 36). Intellectual disability means severe impairments, which appear during an individual's development. The symptoms of the disability can occur in birth, during early childhood or adolescence, but in any case before the age of eighteen. (Kaski 2004, 179.) Disability can also appear later in life for example as a result of an injury or a disease (Koivikko & Autti-Rämö 2006). However, if the disability symptoms occur as an adult it cannot be called as intellectual disability, since the brain has mainly matured into an adult level thus the classification would be brain injury (Kaski et al. 2001).

Intellectual disability means that the person's intellectual performance is significantly lower than the average (Huttunen 2015.) Intellectual disability occurs in many different capability areas, and it broadly weakens a person's everyday survival for example in self-care, communication, movement, learning, and social skills areas (Pihko et. al. 2014, 90). Besides the problems in different capability areas, the person can have other capability areas in which capability is normal (Koskiniemi & Donner 2004, 175).
The variability of symptoms and problems among the intellectually disabled people varies from mild to very severe. Therefore, it is good to take into account that there is no typical intellectually disabled person. Intellectual disability is an umbrella term, which can be divided into smaller sub-categories according to the symptoms. (Arvio & Aalto 2011, 12-37.) Usually, an intellectually disabled person has multiple different disabilities, which will bring more challenges to cope with in everyday life (Pihko et. al. 2014, 90). However, intellectual disability describes the overall difficulties of survival (Koivikko & Autti-Rämö 2006, 1907-1908).

Intellectual disability can be caused by many different reasons. There are four main reasons for intellectual disabilities: genetic, acquisitions, multifaceted, and unknown reasons. The most common cause of intellectual disabilities is different syndromes and genetic reasons (Malm et al. 2004, 167). The causes are more easily detected and diagnosed in mild intellectual disabilities than in severe disabilities (Kaski et al. 2001). Usually, in severe disabilities, the genetic factors are the main cause of an injury (Pihko et al. 2014, 90-93.) It is also quite common that the causes of intellectual disability are unknown and remain completely unclear (Huttunen 2015). The impact of social economy class has been studied in mild disabilities; the combination of poor social status, bad living conditions, and the low educational level can cause so-called inherited intellectual disabilities (Castle 1998, 323).

The most significant period for disabilities to develop is fertilization, prenatal period, and early childhood  (Arvio & Aaltonen 2011, 39). Intellectual disability might occur during pregnancy for example due to various microbes or mothers' use of alcohol and drugs (Huttunen 2015). However, some intellectually disabled children might have suffered the oxygen deficit during the childbirth. Also, different damages in the central nervous system caused by different illnesses and infections, or accidents in childhood can cause intellectual disabilities. (Kaski 2002, 148.)

### 3.1.2 Disability levels

According to the World Health Organization (WHO 2016), intellectual disability is divided into four different sub-groups based on the intelligence quotient (IQ); mildly, moderately, severely and profoundly disabled. The IQ level's determination for distinction is often difficult and therefore in practice intellectual disabilities are often divided only into two groups, mild and severe disability (Kaski 2002, 147). However, the division between the different disabilities are based mostly on the IQ. There are also some other general principles on how various intellectual disabilities are divided. The general population's normal IQ score is between 80 and 120 points, and intellectually disabled people's IQ is below 70 points. (WHO, Kaski et al. 2002, 22-23.)

The mild forms of intellectual disability are much more common than the more severe disabilities (Kaski et al. 2002, 25). Most of the mildly intellectually disabled people are mostly able to take care of themselves independently (Pihko et al. 2014, 91). Mildly intellectually disabled children may go to normal school with various forms of support, but needs often some kind of special education, because of different learning difficulties. Although mildly intellectually disabled people are quite independent in most areas of life, they need some support during their whole life. (Kaski, et al. 2002, 25.) Mildly intellectually disabled person's IQ is in between 50 to 69 points (WHO 2016).

Moderately intellectually disabled people have difficulties in taking care of themselves. Moderate disability causes significant delay in the child's development and the child needs special education and various school support methods. (Kaski et al. 2002, 25.) They have considerable difficulties in reading and writing (Arvio & Aaltonen 2011, 22). The level of language skills varies between moderately disabled children, and some may have sufficient communication skills. Most can manage, either independently or quite independently with their personal daily activities. (Kaski et al. 2002, 25.) IQ score between 35 to 49 refers to moderate intellectual disability (WHO 2016).

Most severely intellectually disabled people need constant support and guidance in all of their daily activities (Arvio & Aaltonen 2011, 22). The school is required to provide substantial support measures. A person with severe intellectual disability is dependent on other people. Although rehabilitation is demanding and can be a long process, the rehabilitation can enhance the chances of the disabled people to handle their daily activities more independently. (Kaski et al. 2002, 26.) Severe intellectual disability IQ score ranges from 20 to 34 points (WHO).

Profound disabilities occur less frequently, only about 3 per cent of intellectually disabled people are profoundly disabled. Profoundly intellectually disabled people need constant care. They have problems in all development areas. Also, the problems in development increase over the years because the speed of the development of the disabled people is slower. (Koskiniemi & Donner 2004, 175.) Profoundly intellectually disabled people can learn things related to daily life situations, as well as body movements and communication. The movement and communication. Profoundly intellectually disabled people can become self-reliant in some activities of daily living, such as eating. (Kaski et al. 2002, 26.) IQ of less than 20 points refers to profound intellectual disability (WHO).

The term ‘multiple intellectual disability’ has no precise definition. In practice, it means that besides the intellectual disability, the person has an additional disability, which decreases the person’s functional ability. Additional disabilities can be for example, physical disabilities or sensory impairments. In general, profoundly intellectually disabled people have always some additional disabilities or diseases. The most common are speech impairment, epilepsy, physical disability, or any sensory impairment. (Arvio & Aaltonen 2011, 15.)

In addition, different mental disorders are more common among intellectually disabled people other population. Mental disorders are common among children with intellectual disabilities but often undiagnosed. (Kaski 2004, 191-192.) According to Koskentausta (2006), up to even 33 per cent of intellectually disabled children have some kind of mental disorder (Koskentausta 2006, 40). Also, autism syndrome is common with intellectually disabled people (Kaski 2004, 191-192).

Physical disability means difficulties in movement, which causes limitations in everyday life. Usually, people with physical disabilities need various mobility aids. It is important to take into account that physical disability is different than intellectual disability. However, an intellectually disabled person can also be physically disabled, but a physically disabled person isn’t necessarily also intellectually disabled. Physical disability in its various forms is the most common form of disability. The causes for physical disabilities are either congenital or a result from accidents or illnesses. (Malm et al. 2004.) Today, a more appropriate term for physically disabled person is physically limited person (Airaksinen 2006, 21). CP-disability (Celebral palsy) is one form of physical disability. Cerebral palsy is a syndrome that ranges from mild to very severe disorder of disability. The symptoms of this syndrome vary a lot with different people, but the disability in itself is very distinct and differs from other disabilities. The mental development of a large proportion of people with cerebral palsy syndrome is normal, but with about half of the people with the syndrome, the development can be mildly or severely delayed. (Malm et al. 2004, 278-281.)

### 3.1.3 Special needs

The distinction between intellectual disability and neurological special needs is problematic to make. Usually, special needs are not as severe by nature, and have less effect to the person's abilities than intellectual disability. (Arvio & Aaltonen 2011, 24-25.) There are more people with different special needs than people with intellectual disabilities. Moreover, intellectually disabled people may have some neurological special needs too (Koskiniemi & Donner 2004, 175).

Special difficulties can have an effect to either one or multiple sectors of development. If the special needs occur in two or more development sectors, it is called broad spectrum of special needs. Usually, a person with broad spectrum of special needs has lower IQ than an average person, which may have a huge effect on the person's life. In turn, only one difficulty or mild special needs problem might not have a major effect on the person's everyday life and in a situation like this, the IQ of the person is usually normal. (Arvio & Aaltonen 2011, 25-27.)

The severity of the special needs vary a lot. The special needs mean problems in for example, linguistic, motoric, or perception skills. Special needs can also mean problems in concentration, in enterprise resource planning system or problems with social skills. Linguistic difficulties can be for instance, disturbance or abnormal development of speech production, understanding or naming things. Motoric difficulties refer to problems in fine or cross motor skills, sensory processing or dyspraxia problems. Perception problems mean for example, problems in visual perception skills or body perception. (Arvio & Aaltonen 2011, 27-29.)

According to Herrgård and Renko (2000), today the children's most common special needs are different concentration problems. Also, language development problems as well as learning difficulties are very common today. (Herrgård & Renko 2000, 2038.) Typically, special needs occur before the child's pre-school age, and are multifaceted and long-term by nature. Most of the children are given different rehabilitation therapies. The reasons behind the different special needs are usually genetic as well as environmental. (Arvio & Aaltonen 2011, 24-25.)

## 3.2 Disability in Finnish culture

In Finland, disability is not as observable as it is in Somalia. According to Mölsä (2012), disability in Somalia has traditionally considered only visible injuries such as, physical disabilities. In Finland disability is considered to be a broader issue than in Somalia; for example, children's ADHD, Asperger's syndrome, and autism are not considered disabilities in Somalia. (Mölsä 2012, 60-62.)

Leppälä 's (2014) research shows that the concept of disability in Finland has changed significantly over the decades (Leppälä 2014). The attitudes towards the disabled people were discriminatory in the 1800 - 1900 centuries. The belief was that disability is a curse from the God. (Teittinen 2012, 65-67). During the 1940's disabled people were a specific group who lived outside the main society. At that time, it was highlighted that the mentally retarded persons bring various efforts for the society, and it required protective measures from the state to protect the society. However, since the 1950s, hospitals and various institutes for disabled and psychiatric patients were established in Finland to a larger extent compared to in many other countries. (Anttinen 1990, 60-61.)

In Finland, thoughts about disabled people's rehabilitation and social rights arise in the 1960s. Individual's rights started to be more important than the benefits of the society. The concept of mental retardation started to be offensive, and it changed for the more neutral concept of intellectual disability. The attitude changes especially among disabled children's parents when they started to defend their children and families' rights. (Leppälä 2014.)

In the 1970s and 1980s the secretion systems for the disabled were dismantled and the disabled people's status was secured. Finnish people began to think that people with disabilities have the right to belong into the society, and that they have a right to similar standards of living as everyone else. To reach this object, the general service systems were made available for people with disabilities as well. Different support services for disabled people were also provided in order or promote equality. In 1970-1980 the attitudes towards disabled people changed for more open-minded and appropriative. (Leppälä 2014.)

According to Teittinen (2012), understanding disabilities in Finland is strongly medical nowadays. In 2000s major structural changes have been made in disability health care. Thus, the services have been developed and re-organized during past few years. Disability is still seen as a burden, which tried to be regulated through various legislation and services. (Teittinen 2012, 74.)

### 3.3 Diagnosing

Diagnosing the intellectual disability varies depending on the causes of the disability, and the severity of the disability. Some inherited diseases, chromosomal defects and neurological-developmental disorders can be diagnosed in early pregnancy, some at a later stage of pregnancy or on a new born infant. (Kaski 2002, 148.) Severe intellectual disabilities, sense impairments, and celebral palsy should be detected during the child's first year (Herrgård & Renko 2000, 2038: Arvio & Aaltonen 2011, 18).

However, in most cases the intellectual disability occurs as a slow mental development of an infant, toddler or pre-schooler and will be diagnosed later. (Kaski 2002, 148.) If the child has not received certain skills before the expected age, the child is referred to further examinations (Kaski et al. 2009, 29). Also, the child's development may slow down, stop, or he or she can even start to loose learned skills. (Kaski 2002, 148.) If the child loses development skills, further examinations should be done immediately (Herrgård & Renko 2000, 2038).

If there is a reason to suspect that a child has a developmental problem, usually a physician and a psychologist conduct the preliminary examinations in a municipality health care centre or in a family health clinic (Kaski et al. 2009, 29). If something indicates that a child might have an intellectual disability, further examinations are necessary. These examinations are made in special health care sector. Intellectual disability diagnosis is mainly based on the examination results of the doctor (paediatric) and a psychologist / neuropsychologist studies. Moreover, the examinations may be supplemented with speech- and occupational therapies assessments. (Pihko et al. 2014, 92.)

In Finland, intellectual disability is always diagnosed in special health care (Pihko et al. 2014, 90-92). After the intellectual disability diagnose, the child becomes a customer of intellectual disability care (Kaski et al. 2009, 29). Also, the diagnosis for the children with special difficulties is essential. If the child is suspected to have problems in development, the multi-professional teams are again needed. These teams may consist for example of a doctor, psychologist and a therapist. If there is no reason to suspect any intellectual disability, the examinations can be done in primary health care. (Arvio & Aaltonen 2011, 24-33.)

The doctor's (paediatrician) part in diagnosing the intellectual disability is mainly related to finding the causes of the disability. Often a paediatrics' research is extensive and involves a number of different sections such as, the health history of the other members of the family, the child's fetal-period, and infancy. (Arvio & Aaltonen 2011, 17.) Laboratory and imaging examinations are often needed for the diagnosis, such as chromosomal and DNA examinations and the magnetic resonance imaging of the head (Kaski et al. 2002, 38). ICD-10 Classification of Diseases (F70-F79) sets out the criteria which are needed for the intellectual disability diagnose (Arvio & Aaltonen 2011, 17-19).

Psychologist's task is to determine the severity of the intellectual disability. The psychologist determines the intellectually disabled person's development and intelligence level. (Kaski et al. 2002, 28.) Psychologist uses standardized intelligence tests to determine the individual intelligence quotient (IQ), as well as child's developmental age. The psychologist tests measures for example, attention skills, language functions, motor functions, perception, memory, performance management, and sociability. (Koskiniemi & Donner 2004, 135.) Psychological research is used in diagnosing and making the rehabilitation and service plan. (Arvio & Aaltonen 2011, 19.)

Therapists such as, speech, - physio, - and occupational therapists clarify the intellectually disabled child's functional understanding (Arvio & Aaltonen, 2011, 17). The occupational therapist evaluates intellectually disabled child's functional capacity and the survival in everyday life. The main focus of the assessment is to evaluate the daily living. In addition, the occupational therapists evaluate the playing and social skills, sensory functions and perception skills. Furthermore, in occupation therapy the child's motor skills such as fine and gross motor skills, and eye hand co-operation skills are evaluated. Occupational therapists also assess the need for any implement tools. (Kaski et al. 2002, 282-283.)

Speech therapist evaluates child's communication skills, such as speech production and speech comprehension and understanding. Speech therapist also measures the need for tools that support communication. (Kaski et al. 2002, 276-278.) Physiotherapist is needed when the disability is related to physical injury (Review & Aaltonen, 2011, 17). Moreover, therapists' research results will also be utilized in the diagnosis and planning of rehabilitation. (Kaski et al. 2002, 276)

Finding the disability level, and the reasons behind the intellectual disability are important for the prognosis, treatment, rehabilitation, and the education plan. There are also different health risks for certain disabilities that are good to know as at the earliest possible state. In addition, awareness of reasons for the disability can erase guilt related to pregnancy and childbirth. (Pihko et al. 2014, 92.) The exact diagnosis will also help obtaining the statutory benefits (Arvio & Aaltonen 2011, 18). However, the exact cause is often hard to know, but it can be concluded whether the disability is hereditary or a result of external factors. If the cause of the disability is not clear, there is a need for further investigation. On the other hand, long examination processes are usually expensive, tiring and painful for the children and families. (Pihko et al. 2014, 92.)

### 3.4 Legislation behind the services

The purpose of defining disability is to find the right people in the need of help, and give them the right care and services. Different disability definitions serve different purposes. (Savtschenko et al. 2010, 68.) Disabilities can extend from mild to severe, and therefore the differences in the treatments and services also vary a lot (Koivikko & Autti-Rämö 2006). Especially, definition as a severely disabled person confers the right to specific financial benefits (Malm et al. 2004, 12-13.) According to Nouko-Juvonen (1999), disabled people's services include number of welfare and healthcare services, rehabilitation services, financial support as well as education and labour administration services (Nouko-Juvonen 1999, 35). Services for disabled people are for example, personal assistance and assistants, weekend and evening care, teaching, interpreting services, assistive devices, as well as different financial supports and home modifications. (Kehitysvammaliitto 2016).

In Finland the legislation supports and ensures the intellectually disabled people's special status and the availability of the certain services (Koivikko & Autti-Rämö 2006, 1907). In Finnish law, the disabled person's rights are based particularly on the constitutional law's (1999/731 6§), fundamental rights. According to the Finland's constitutional law, disability services are primarily determined in the social care general law, the Social Welfare Act (2014/1301). If the Social Welfare Act does not provide adequate assistance and support services to a disabled person, may the services be supplemented based on the *Special Health Care Act* (1977/519). These laws are, the *Disability Services Act* (1987/380) and the *Intellectual Disability Act* (1977/519).

The Disability Services Act (1987/380) is the preliminary act to regulate the special services for all the disabled people. Disability Services Act can also be used at itself, if it guarantees better services for the disabled people than the Social Welfare Act. Disabled Act (1987/380) is designed to complement the general social services and income security. Disability Services Act is the primary law for Intellectual Disability Act (1977/519). With intellectually disabled people, Intellectual Disability Service Act (1977/519) is always needed if the services of the Disability Services Act are not sufficient or suitable. (THL 2015) The municipalities' social services are responsible for the supply and practice of Social Welfare Act and Special Health Care Act. In Finland different municipalities have used slightly different services with disabled people. (THL 2015) Laws that affect disabled people are also for example, Day Care Act, the Basic Education Act, the Act for Disability Benefits and the Interpreting Services Act. (Kehitysvammaisten tukiliitto 2016.) According to Social Insurance Institution of Finland (Kela), intellectual disabled persons are eligible for different types of financial compensation due to the disability. Kela's benefits and types of services are; pension, disability and care allowances, rehabilitation and therapies, as well as compensation for example, to medicines and travel costs. (Kela 2016.)

## 3.5 Rehabilitation

In Finland the rehabilitation for disabled people is based on the health care act (Terveydenhuoltolaki 1326/2010). In Finland, all the medical rehabilitations, like occupational therapy and speech therapy as well as neuropsychological rehabilitation are arranged by the public health care sector, special health care, or the Social Insurance Institution. (Pihko et al. 2014, 216.) Rehabilitation organized by Kela, is measured in the law 566/2005. Intellectually disabled children's medical rehabilitation is always on Kela's or special health care's responsibility. (Kela 2016.) Children with special difficulties might get therapies organized by the public health sector (Helsinki city 2016).

The traditional thinking about rehabilitation has included the idea that disability is an illness or problem, which must be rehabilitated. Today, the thinking is wider, and it is considered that a disabled person needs help and support in certain matters of life in order to be able to live meaningful and satisfying life. (Arvio & Aaltonen, 2011, 178.) The general goals of disabled people's rehabilitation are to recover from the lost functions, prevent the individuals from losing their ability to function, promote participation, reduce environmental barriers, and encourage and assure personal growth. (Arvio & Aaltonen 2011, 182.) Especially among children's rehabilitation, the whole family's welfare is important (Rissanen et al. 2008).

Depending on the child's age, the nature of the help and rehabilitation differs. According to the Finnish Paediatric Neurology Association (2010), intellectually disabled child's good rehabilitation includes various individual or couple or group therapies as well as child's network, such as parents, kindergarten and school counselling. (Kiviranta et al. 2016, 5) In the child's early childhood diagnostics and different medical services are important, and not much other rehabilitation is needed. (Pihko et al. 2014). In addition, parents' support, advice and assistance play an important role. Later in the childhood various therapies such as occupational and speech therapy are important. (Kaski et al. 2002, 286-284: Pihko et al. 2014, 216.) In play- and school age the educational rehabilitation is in a big role. At a school age, the child's rehabilitation might include various activities and hobbies. The intellectual disabled person's rehabilitation in different forms is often life long (Arvio & Aaltonen 2011, 178.182). The child's rehabilitation is usually planned there where the diagnosis is done. According to Pihko et al (2014), the rehabilitation is based on the versatile and overall assessment of the child's situation (Pihko et al. 2014). The therapy aims are set together with the professionals and the child's family (et al. 2016, 5) Rehabilitation aims' are to maintain and improve the child's function and development. (Pihko et al. 2014, 210.)

# 4 Research methods and research questions

Firstly, in this chapter the research questions are presented. Secondly, the research methods that have been used in the study: the case study form, qualitative research method, and semi-structured interview are introduced. Finally, the participants in this study are described and then the data collection process. The description of the data collection process is done very precisely, because the aim was to highlight the challenges encountered, which are essential also in terms of the research and the final results.

The chosen research methods depend on the purpose of the research (Tuomi & Sarajärvi 2004, 73). According to Tuomi and Sarajärvi (2004), the framework of the research is determined by the research questions, the guiding methodology, and previous knowledge of the topic (Tuomi & Sarajärvi 2004, 18, 27). In the present study, the data was collected and analysed through methods that are relevant to studies concerning immigrants' experiences about disabled child's health care and rehabilitation.

The study follows qualitative research method, and uses a case study. The research data has been collected by individual interviews using a semi-structural interview method. In the study, the used analysis method is the content analysis model.

In accordance of the aims of the present study, four research questions were formed:

1. How do the participants view disability in Somali culture?

2. How do the Somali parents experience the health care and rehabilitation services for their disabled child in Finland?

3. How are the cultural issues taken into account in the disabled child's health care and rehabilitation services in Finland according to the Somali parents?

4. What kind of improvements could be done for the disabled child's health care and rehabilitation services in Finland from Somali parents' point of view?

## 4.1 Qualitative research and case study

According to Hirsijärvi et al. (2004), a qualitative research is a description of a real life (Hirsijärvi et al. 2004, 152). In a qualitative research, the research questions are intended to be understood and explained. As a result, a qualitative research is often referred to an understanding research. (Tuomi & Sarajärvi 2004, 18-27.) The purpose of this study is not to provide statistical generalisation. Therefore, the results are not intended to generalize all the Somalis with disabled children's experiences and opinions. The main purpose is to produce detailed knowledge by using couple of cases and therefore, the present study can be called a case study. (Eriksson & Koistinen 2005.)

A case study's purpose is to describe a specific group's individual problems, trying to create as comprehensive view of the matter as possible (Eriksson & Koistinen 2005). In the present study, the purpose was to create an all-encompassing view of the four Somali participants. Even though the case study usually examines only one or two cases, the produced information can be used later when examining similar cases and explaining similar incidents (Syrjälä et al. 1994, 10-15). According to Eriksson and Koistinen (2005), the purpose of a case study is to examine, define, and analyse the certain cases, and finally find solutions for them (Eriksson & Koistinen 2005, 4-34).

According to Syrjälä et al. (1994) "in a case study the examinees are seen, as sensing, acting and participating subjects" (Syrjälä et al. 1994, 10-15). The participants in the study were subjects of their own lives and not viewed as objects. Furthermore, quotations are used in order to illustrate participants' views. According to Syrjälä et al. (1994), direct quotations are a good way to bring up the participants' voices in research (Syrjälä et al. 1994, 10-15).

According to Saarela-Kinnunen (2001), there is no clear definition for the case study because it can be carried out and analysed through various data collection methods (Saarela-Kinnunen & Eskola 2001, 159). In this study, interviews are used as the data collection method. More specifically, the interviews were carried out by a semi-structural interview method. Finally, the data was analysed by using a content analysis method.

## 4.2 Interview

In qualitative research, interviews are one of the most common data collection methods (Hirsijärvi & Hurme 2009, 34). Interview as the research method was chosen because it was considered to be the most appropriate method for the purposes of the present study. As Hirsijärvi and Hurme (2001) emphasise, the idea of an interview is to convey information about the interviewee's thoughts, perceptions, feelings, and experiences (Hirsijärvi & Hurme 2001, 41). All the chosen research questions in the study are related to participants' personal experiences and thoughts.

Another reason the interviews were chosen was due to the fact that the subject might be sensitive and difficult for some participants. In addition, from my experience child's disability is a sensitive subject especially in Somali culture. I consider that talking about emotional, and intimate issues is more natural in an interview than for example, through questionnaires. Also, Hirsijärvi and Hurme (2003) point out that in the interview the person has a better chance to talk more diversely about a certain subject (Hirsijärvi & Hurme 2000, 34-35). Additionally, in an individual interview it is usually easier to be open and truthful compared to group interviews. According to Hirsijärvi and Hurme (2000), the interviewer has a better chance to interpret the questions and make additions (Hirsijärvi & Hurme 2000, 34-35.), which I also considered very important.

The interview structure can be different depending on the used situation and the research purposes (Hirsijärvi & Hurme 2009). According to Metsämuuronen (2006), the interview methods are usually divided into three main types: structured, semi-structured, and open interview (Metsämuuronen 2006, 234-235; Hirsijärvi & Hurme 2000). In this study, the semi-structured interviews were used. The chosen interview method was selected together with the workplace co-operation partner for several reasons which are described below.

The semi-structured interview was suitable for the study, because it is good in situations when discussing subjects which the participants are not used to (Hirsijärvi & Hurme 1995, 35-41). In a semi-structured interview, the questions are the same for all the participants, but the interviewer may change the question order and phrase the questions to suit a certain situation. Moreover, the theme and perspective are pre-decided, but certain variations are possible as the interview progresses. (Hirsijärvi & Hurme 2009.) For this study, there were certain matters that were to be investigated so the interview themes and specific questions were planned beforehand. Some of the interview questions arise from the workplace needs and were also background of the research questions.

In the semi-structured interview, the participants can answer questions in their own words and the answers are not tied into specific answer options. (Hirsijärvi & Hurme 2009.) This was considered very important in this study because the aim was to get thorough answers about intimate and sensitive issues. The semi-structural interview was also a suitable option because of its flexibility as the target group consisted of variety of people to whom the questions could affect differently. In this kind of situation, it is good to have the option to use your own judgment in the selection and formation of the questions and take the cultural issues into account.

Another reason for choosing the semi-structural interview was to make the interview situation feel like a genuine conversation. According to Hirsijärvi and Hurme (2000), the themes in semi-structural interview bring freedom and flexibility so that the interview is closer to a discussion (Hirsivjärvi & Hurme 2000, 103-104). On the other hand, interview is a lot slower data collection method compared to for example, a survey research (Hirsijärvi et al. 2004, 184). A survey could not been used in this study because of the language differences. Most of the interviews were done in Somali language by using an interpreter.

## 4.3 Data collection

Finding the participants started actively in May 2016. The purpose was that Hilma organisation would find the suitable participants for the interviews together with me. The interview invitation was placed on Hilma's Internet page, Facebook, and Newsletter. The invitation letter was written in Somali language and in Finnish (appendix 1 and 2). The subject for the study was also presented at the Hilma's network meeting.

I tried to search potential participants through different channels. I was in touch with 17 different organizations and non-governmental associations in order to find suitable participants. I was in touch via e-mail with different organisations including Somali organisations and disability organisations for example, Somaliliitto, Somaliverkosto, Suomen Somalialaisten liitto, Suomi-Somalia seura, Finnish Somalia Network, Espoon monikulttuuriasiain neuvottelukunta, African Care, Monica-Multicultural Women's Association, and Kehitysvammaliitto. In addition to my and Hilma-organizations attempts, also the Somali interpreter tried to search suitable people for the interviews. Usually, Somalis have large families and the community is important (Tiilikainen 2013), therefore we considered that the best way to get suitable participants could be just to ask straight from the acquaintances or relatives.

Despite the great effort, neither Hilma organization nor I found anyone willing to take part in the interview. None of the organizations to which I had been in contact with could find suitable participants. Hilma organization could not find anyone suitable either. Finally, during the summer 2016, the Somali interpreter found three Somali women who were willing to take part in the interview. Getting the sufficient data was extremely difficult. The initial wish was to have more data than three interviews and there were no men participants. After realizing the data collection difficulties, I decided to get a new perspective for the study. I decided to interview the interpreter and the Somali culture specialist Marja Tiilikainen to find out the reasons for why it was so difficult to obtain participants. (appendix 4 and 5). After the interview with the culture specialist, I got one more Somali man to participate in the interview.

The final participants in the interviews were four Somalis; three women and one man. The interpreter organized three of the interviews and the Somali culture specialist organized one interview. Three of the interviews (Somali women) were conducted in Somali language through the Somali language interpreter. The Somali man did not need the interpreter because of his good language skills. In addition, I interviewed the Somali interpreter and Somali culture specialist Marja Tiilikainen for the reason to get more information about Somali culture, especially understanding Somali culture's health perceptions and disability in Somali culture. In the analysis part, I mainly analyse the Somali parents' interviews. However, in some parts the interpreter and specialist’s views are presented as well.

The Somali parents filled in the consent form (appendix 6) and the interpreter filled in the interpreter’s confidentiality agreement (appendix 7). The interviews proceeded in a typical way for semi-structured interviews. Certain pre-selected themes and questions were used and there was a slight variation between the question order and additional questions. (Hirsijärvi & Hurme 2009, 47.) During the interview the forms and order of the questions changed sometimes, which is natural for a semi-structural interview Hirsijärvi & Hurme 1995, 36). It certainly made the interview situation more like a conversation.

At the beginning of the interview, participants were asked to give permission to record the interview. All the interviews were recorded and the tapes were destroyed after the transcription. After the interviews each of the interviews were transcribed. The transcription was carried out as exact as possible although some of the meaningless vocal outbursts such as "hmm" and "aha" marking were not used. Transcription was very important for remembering everything correctly. It also facilitates the processing of the material in the next stage, in the actual analysis part. The transcriptions were also destroyed after the use.

The interview questions were formed together with Hilma organization (appendix 3). Firstly, the interviewee's background information was asked such as living time in Finland, place of residence, and Finnish language skills. The background information part was important to get information about the person’s basis. In the next theme the questions were related to the child with special needs’ background information. The questions contained more details about the child’s needs; what kind of special need does she or he has and when the developmental delays were realized, and by who. The second part also included questions relating to the child with special needs; whether the child has been diagnosed and when and where the possible diagnosis has been given. The second part’s questions were intended to understand the situation with the special needs child and to clarify the child’s special needs.

On the third theme, the questions include clarification about what kind of treatments and rehabilitation the child has received for example, various therapies, kindergarten, and school support. In addition, what kind of services the family has gotten for instance, guidance, peer support, adaptation training, financial support, and taxi services, etc. In the third part, it was examined whether the parents agree with the health care professionals about the child’s health care and rehabilitation, and whether they are aware of the different forms of various rehabilitations.

In the last part, parents' experiences about the health care and rehabilitation services and the kind of services they have received related to the child's childcare and rehabilitation were examined. It was also examined whether the parents have been satisfied with the services, and whether they have received support and Somali language interpreter when needed. In the last part, possible service improvements were investigated and that was the third research question. The purpose of this part was also to find out the kind of support the participants wish or need in the future and how the health care and rehabilitation services for children with special needs should be improved.

## 4.4 The data analysis

The final research data has been analysed by using a content analysis method. According to Tuomi and Sarajärvi (2003), the content analysis method can be used in all qualitative studies. The content analysis intends to create a clear and coherent description about the results and in this study it is related to the Somali parents' interviews. Through content analysis method the information from the results increase and it is possible to get more reliable and accurate conclusions. (Tuomi & Sarajärvi 2003, 107-110.)

According to Tuomi and Sarajärvi (2009), there is not one specific model for the content analysis, and it can be applied in many different ways (Tuomi & Sarajärvi 2009, 91). The themes were built around the research questions. Eskola and Suoranta (1998) also suggests that in the thematic part, themes may be raised which are related to the research questions (Eskola & Suoranta 1998, 175). Under the main theme categories, sub-categories are formed. Tuomi and Sarajärvi (2003), describe that the used analysis way in the study is as abductive analysis. Abductive analysis can also be called a theory-bound analysis. In the abductive analysis, the researcher has previous knowledge of the subject, which controls the analysis and supports in that. In the theory-bound analysis, the earlier theory does not necessarily test the new theory, but it also aims to create new ways of thinking. Abductive analysis proceeds with data based, but at the end of the data, the earlier theory and the benefit of it guides the analysis. (Tuomi & Sarajärvi 2003, 98-99.)

In the analysis part, the quotations from the interviews are used under the themes. After themating the results the case description of every interview is made. In the description part through the early made themes, connections are found. Finally, the results are compared to the existing theory and research (Tuomi & Sarajärvi 2003, 114-115).

# 5 Results and conclusions

This part of the thesis brings together the results of the study, which are discussed and analysed in the light of previous studies. The results of this study are divided into four sections according to the research questions they refer to. Firstly, the participants' views towards the disability are introduced. Most of the results concerning this subject did not come directly from the participants, but was for example observed from other things such as non-verbal communication and difficulties in receiving the participants in the interviews. In addition, not only the Somali parents' but also the Somali interpreter's and the Somali culture specialist's points of views are presented.

Secondly, Somali parents' opinions and experiences towards the disabled child's health care and rehabilitation services in Finland are introduced. Then the discussion moves on to the cultural issues; how the cultural matters are taken into account in the disabled child's health care and rehabilitation services in Finland from Somali parents' point of view. Finally, the improvement ideas concerning the disabled child's health care and rehabilitation services in Finland from the Somali parents' point of view are presented.

## 5.1 Views concerning disability

One of the aims of the study was to find out what kind of views the participants have about disability in the Somali culture. There was only one straight question in the interview relating to this topic therefore most of the received results are based on the participants' attitudes and non-verbal communication as well as the difficulty of getting participants for the interview. Furthermore, the Somali interpreter and the Somali culture specialist's opinions were heard concerning this subject.

It was clear from the interview situations that disability is a very difficult subject for most of the participants. It also became clear that disability is an untold subject in the Somali culture. Some of the participants said that having a disabled child is a big shame, and those who have a disabled child remain in seclusion. One participant felt that people with intellectual disabilities are avoided. Moreover, one of the participants has not ever seen another disabled child. The findings are in line with Mölsä's (2012) study that disability is a taboo and not spoken aloud in Somali culture (Mölsä 2012, 60-62). In addition, the Somali culture specialist Marja Tiilikainen had similar views concerning disability in Somali culture. Two of the Somali participants emphasized:

> It is very common that immigrants feel shame, because of their child's faults, or how to say, child's problems.
>
> The others avoid us. As long as he has been alive we have been just with our family.

The Somali culture specialist reported:

> Disability is considered highly shameful, and children with disabilities, especially girls may be kept hidden at home. In Somalia it is often thought that the background of disability is either evil spirits or a curse, in which case the treatment should drive these spirits away- rather than rehabilitation.

Due to the fact that Somalis highly respect Islam, it is quite understandable that Somalis are ashamed of their child's disabilities if they consider that disability is a punishment from the God (Mölsä 2012, 62). According to a few of the participants' answers, some Somali parents who have a disabled child might isolate themselves from the community. In addition, the fact that disability is an untold issue in Somali culture, it may keep some Somali parents from seeking care and rehabilitation for their children. Two of the participants said the following:

> I have many acquaintances whose child is in need of care and assistance, but because the parents deny the issues... It is so hidden. I'm trying to talk a lot to younger mothers by my own example that it is not a shameful thing, and there is different help available.

> I have gotten a lot of comments about my child going to a special school when he is not special. I have to justify a lot of things that my child goes to a special school, as well as my own act. Although I have noticed how much it helped that my child received help.

> I have one acquaintance who would have received financial assistance for the child, disability allowance, but he refused it because "my child is not a disabled." He did not realize that it is just a general term for some special need. After a persuasion he agreed to sign it.

In addition, getting the suitable participants was extremely difficult. According to, Mölsä's study (2012), Somalis do not want to talk about disabilities openly especially with people outside the close family. (Mölsä 2012, 60-62.) This is also in line with the Somali interpreter's views. According to the Somali interpreter, getting the Somali parents for interviews was difficult because of the untold and very shameful matter. Disability is not admitted aloud or it is explained some other way. The Somali interpreter described the following:

> Disability is a very sensitive issue for Somalis. It causes abashment among them. Very often, a big reason for why it was so hard to get people for the interview was the fact that the theme is so difficult to discuss. They do not deal with it, or even think that they have a disabled child. They do not understand why there would be anything to talk about in their child. "There's nothing special about him, so why to talk, there is nothing wrong with him." It was really hard to motivate people to take part in the interviews. It was a process of several weeks.

The participants agreed that giving more information to the Somalis could help the matter that disability is considered as such a shameful issue. Also, giving information concerning the reasons behind disabilities would help the parent's self-accusation. In addition, one of the participants had never seen another disabled person in Somalia although acknowledging that there must be others as well. As Mölsä (2012) describes, it is good to take into account that there is not a specific health care for disabled people in Somalia (Mölsä 2012, 60). Two of the participants said the following:

> For this "shame issue", giving information could be a suitable way. Giving more information to the Somalis would help bringing other people in need together and then they would have more encourage to seek help.
>
> This is a huge grievance, giving more information to them would help. The Finnish health care professionals should give more information.
>
> I have not seen any disabled person in Somalia. This is a first time in my life with my own child that I'm facing this kind of thing and therefore I have a lot to wonder.

The Somali culture specialist's comment:

> In Somalia, children with disabilities do not usually go to a school, and poor families cannot afford to pay for transport etc. In addition, it is thought that the education of disabled children is not useful, because they do not get employed anyway. In particular, girls with disabilities are wanted to be protected by keeping them home.

The different views concerning disability might cause challenges in the health care sector. As Pegg (2004) describes in their study, different conceptions of disability between Finnish and Somali cultures were also clearly observed from the interviews. In addition, one of the participants told about a situation where the differing opinions have caused misunderstandings in the health care sector:

> A Somali family who had a disabled child, but who did not see or admit, that there is anything wrong in their child's development, did not go to the child's clinic, and then the health care professional reported to the child welfare. Also, in situations like this, more information would be needed.

## 5.2 Experiences of the Finnish health care services

One of the aims of the present study was to investigate the Somali parents' opinions and experiences of the disabled child's health care and rehabilitation services in Finland. In my opinion, it was important to first explore Somali parents' general opinions of the disabled child's health care and rehabilitation services because the parents' experiences and opinions are also the base for the health care services' improvement ideas. For this reason, I found it essential to investigate their experiences first.

In addition, the investigation about the Somali parents' experiences of the health care and rehabilitation services, were also the basis for the experiences of the cultural matters. The participants were asked questions relating to the different services that the disabled child and the whole family had received in the Finnish health care. Through various questions, which of the services are considered to be good and what kind of services they find important were examined. All the participants were from the Finnish metropolitan area therefore the experiences concerning the services were also from the capital area.

The results between all the participants were very identical relating to the experiences of the disabled child's health care and rehabilitation services in the Finnish health care. All the participants experienced the disabled child's health care and rehabilitation services to be very good in Finland and they appreciate the services they have received. The participants experienced all the received health care and rehabilitation services very important for their child's development and rehabilitation. In addition, all the participants felt that they have received enough services relating to their disabled child's needs. Most of the participants compared the health care services to Somalia's health care services. Somalia is lacking adequate health care services and rehabilitation barely exists in Somalia. Additionally, all the participants considered that the Finnish health care focuses on the child's developmental problems properly.

In the interviews, there was a strong presence of respect towards the Finnish health care, and all the participants appreciated the services they had received. All of this is in line with Mölsä and Tiilikainen's (2007) study, which showed that Somalis highly appreciate Finnish health care services and are major health care service users, particularly in the metropolitan area (Mölsä & Tiilikainen 2007, 451-453). One of the participants emphasized:

> The Finnish system is very good. I am very happy with all the services I have gotten, and all the services have been great.

It is also good to take into account that Somalia's health care service system is totally different compared to Finland's health care system. Somalia's health care is very insufficient and there is not much rehabilitation available for disabled people. (WHO 2004) This might be one reason why all the Finnish health care services appear good for Somali immigrants. However, the purpose was not to compare the Finland and Somalia's health care services, but the purpose was to find out how the participants experience the health care and rehabilitation services in Finland.

Most of the participants' experiences were positive, but one of the participants told about disagreements with the health care staff in Finnish health care. The participant also considered that the disagreement emerged because of lack of knowledge about the Finnish health care. I think that also health care professionals should take the cultural matters into account when dealing with a person from another cultural background. Two of the participants described the services they have received in the Finnish health care concerning their disabled child's issues as follows:

> I'm really satisfied with the Finnish health care, but all the things should be spoken out openly and tell openly about different matters, as well as disadvantages and benefits, tell honestly about all the issues.
>
> There's always been help when it needed. Sometimes there have been disagreements, but usually they are due to the fact that we do not understand the system.

Secondly, the participants' experiences of the health care professionals are presented. All of the participants have used several health care services and dealed with various health care professionals such as the doctor, different therapists, and rehabilitation professionals concerning their disabled child's health care and rehabilitation. Most of the participants' children have received different types of rehabilitation, such as occupational therapy, speech therapy and physiotherapy.

In addition, all the participants' disabled child has had educational support such as a special assistance, or they have been in a special school or day care. All the Somali parents considered that the Finnish health care professionals' skills are very good. In particular, the doctor was seen as the most important health care professional and doctors' professional's skills were highly appreciated among the participants. As Mubarak et al. (2015) describes, by far the most popular profession among the Somalis is a doctor, and Somalis highly appreciate Finnish education system (Mubarak et al. 2015). I consider that the appreciation towards the professionals and especially doctors was also clear from the participants' answers. Two of the participants described:

> The doctor has been an important helper. He has been very supportive and got things done. Because of him we have received things. It would have been very difficult if the doctor had not been so dedicated.
>
> Everyone has been good, but the doctor directed us well from the very beginning.

In addition, it was clear in the interviews that the participants counted on the health care professionals and the therapists in the matters relating to the health care of their disabled child. The positive attitude was also evident when the participants agreed with the health care professionals about the matters relating to the child's developmental delay. Moreover, different health care services and rehabilitations were seen very important for supporting the disabled child's development. Most of the participants said that they understand the aims for the rehabilitation and the therapy methods. Two of the participants described:

> They have always told what is done there, and what to do at home. Some issues have become to light, which I have not paid attention before. It has been a really eye-opening.

> Good experiences in different therapies. He has developed, it has clearly helped the child, but he still needs it.

Additionally, all the participants have received some other services besides the rehabilitation services for their disabled child. The most common received services were taxi service and financial support (a disability support money). However, most of the participants were not been told about other different services, such as guidance, peer support or adaptation training etc. One of the participants said that the family do not need any peer support because they are able to handle the situation:

> We are provided financial support. No need for peer support, able to self-handle the situation. Either, had the peer support been offered.

Only one of the participants had been told about adaptation training, but the family did not want to take part of it:

> The social worker told us about different possibilities, such as financial support, peer support, and adaptation training. But we did not go to the adaptation training, and it was our own decision.

Finally, I would like to emphasize the participants' challenges understanding the Finnish health care system. When considering the Finnish health care system and taking into account the fact that the system is also difficult to understand even for a native Finnish person, it must be even harder for Somalis. Peltola (2005) similarly points out that the different health care system and Somalia's lack of health care services might cause confusion and complicate the use or services among Somalis in Finland. I agree with Peltola (2005), because as a health care professional myself, I have faced challenges when discussing Finnish health care system and various rehabilitation services with patients from different cultural backgrounds.

Moreover, during the interviews I noticed that there is no word for occupational therapy in Somali language, which is completely understandable because of Somalia's poor rehabilitation service system. According to Peltola (2005), the Finnish social, health and rehabilitation services are criticized by their complexity and dispersion. (Peltola 2005.) The results of the present study showed that understanding the Finnish health care service system was difficult for all the participants. In addition, all the participants agreed that they were not informed properly about the Finnish health care system at any time. Two of the participants described the following:

> Many do not know how the Finnish health care system works. Somalia has never had a similar system.
>
> I do not know the Finnish health care system. It has not been explained thoroughly to us.

It was visible, that the participants have challenges to understand the Finnish health care system, and perceive all the possible services it can include. On the other hand, I did not get clear understanding how much the participants have tried to solve out the possibilities or asked help from the health care professionals. My interpretation of the matter is that the Somali parents appreciate all the support they have received from the Finnish health care, and they do not require any extra services, especially those kinds of services, which are totally new and weird for them. Also, Silvennoinen's (2000) study concludes that Somalis do not admit if they have not understood the care and maintenance instructions or advice (Silvennoinen 2000). In addition, the interviews revealed that the participants do not insist any health care or rehabilitation services for their disabled child and they trust the specialists.

### 5.3 Experiences of the cultural matters

Another aim of the study was to investigate Somali parents' experiences on how the cultural issues have been taken into account in the disabled child's health care and rehabilitation services in Finland. The aim was to find out whether the health care workers have taken the cultural aspects into account when dealing with a Somali customer. According to the interviews, the participants have positive experiences of the respect towards their culture. All the participants considered that the health care professionals have respected them highly.

According to Peltola's (2005) study, many immigrants experience prejudice, racism, and discrimination when looking for support. Those Somali parents, who participated in this study have not experienced negativity when dealing in the Finnish health care sector concerning their disabled child's issues. On the other hand, one of the participants hoped more cultural awareness from the health care professionals. One of the participants described the following:

> There have not been any problems. I have not noticed that our culture would be an obstacle.

> The health care professionals have taken into account the cultural things very well, our culture has been respected. Immigrants have been taken into account in the Finnish health care.

From the interviews it appeared that culture plays an important role also in the health care sector. It was clear from the interviews that different things are easier to understand by the their own culture, and partly for this reason the use of an interpreter was considered important. On the other hand, one of the participants hoped more cultural awareness from the health care professionals. One of the participants said the following:

> All the employees have been really good, but everyone understands things the best by their own culture. Health care professionals should be trained in different cultures.

According to the Somali language interpreter, the culture awareness is never too much, and small things mean a lot and increase the confidence:

> The cultural matters is good to take into account, but not too much because then it will be interpreted as a racist behaviour. Cultural awareness could be increased among the health care professionals, such as those basic things and rules, for example that you do not start to shake hands with a Somali man. When you have the knowledge then it will also create confidence and the person is easier to listen to. This is how a Somali feels their self welcome.

In this culture theme section the purpose was also to investigate whether the Somali language interpreters have been used when necessary. Like Mölsä and Tiilikainen (2007) argue, different languages can obviously cause language barriers between Finns and Somalis in the health care sector. In addition, it is good to take into account that most of the elderly Somalis do not speak Finnish and therefore the use of an interpreter is essential. (Mölsä & Tiilikainen 2007, 453.)

Also, all the participants in this study shared the view that the use of an interpreter is important in the health care sector. The participants have lived in Finland between 11 and 26 years and three of the participants considered that their Finnish language skills are very poor. Only one of the participants had good Finnish language skills. All the participants agreed that they understand Finnish language better than they speak it. Most of the participants rather speak their mother tongue, especially when talking about important things relating to their child’s issue. As Perhoniemi (2006) emphasizes that although the Finnish language is slowly becoming a more integral part of everyday life among the Finnish Somalis, Somalis still rather speak their mother tongue. One of the Somali mother described the following:

> Yes, the interpreter is really important. The interpreter allowed me to follow the topic.

All the participants agreed that the Somali interpreters have been used whenever it has been necessary. The use of an interpreter was offered for all the participants in the Finnish health care. One of the participants said that the use of an interpreter has been a self-evident issue. One of the participants described the use of an interpreter:

> Interpreter services have been adequate, they have always been offered for us. Whenever there is a meeting where there are therapists and others, there is an interpreter as well. It has always been like that.

On the other hand, two of the participants wished that the interpreters would be specialized in the Finnish health care and children's neurological problems to be more adequate in the translating situations. Also, the interviewed Somali interpreter argued that Somali interpreters need to get more education, and especially understand the more of certain matters. It would be good to use the same interpreters whenever it is possible. The Somali interpreter described:

> It is a big problem when the interpreter does not know properly known the subject the patient and doctor are talking about and then should explain those thing properly to the customer for example, some social office's customs, and they do not understand the things either, so it becomes jargon and in the end everyone is confused. The interpreter is important to understand the whole integrity very well before interpreting.

Also the Somali culture specialist had opinions concerning the use of an interpreter:

> The use of an interpreter makes it possible to communicate, can help to understand the cultural meanings as well as help in finding people. On the other hand negative aspect can be for example, the interviewees' fear that the information will spread in their community. The fact that the interpreter was familiar for the participants probably added confidence and some might have participated because of the interpreter.

Some of the participants considered that there is no need for an interpreter when they are dealing in the Finnish health care because there is always a family member who can speak Finnish. It was not said straightforward in the interviews, but the interpretation is that the participants rather use a family member as an interpreter than an unfamiliar interpreter. This claim is also in line with Mubarak et al. (2015) that many Somalis prefer to use family members as their interpreter (Mubarak et al. 2015, 206-208). In addition, according to the interviewed Somali interpreter, it is relevant that the interpreter is familiar to the customer for many reasons. The Somali interpreter described:

> The thing that I have been familiar interpreter for the interviewed Somalis has helped a lot in this case. Then there is another thing, if the client and the interpreter do not know each other at least directly, it can easily become a situation where the interpreter may impose their own ideas to the client. Then it is definitely not professional. And that happens. But if the interpreter is familiar

> to the client, a relative or so then the interpreter is really useful. Then the person respects the other person and explains things properly, and do not leave anything unsaid. The use of an interpreter is a two-sided matter.

One of the Somali women described:

> Interpreters have always been offered, but we can speak Finnish, so there has been no need.

An interesting matter, which arose from the interviews, was that Somali women (mothers) are more responsible for the disabled child's care and other things. Somali mothers take the child to health care services, and participate in the care and rehabilitation planning more than Somali men (fathers). Also, according to the Somali father, who was the only participated man, the mother takes care of the child's things more than he does. This is in line with Mubarak et al. (2015), and Tiilikainen (2013, 2009) study, which has investigated Somali culture's gender roles. Roughly put, childcare belongs to the women and family girls, and parenting is mainly the mother's responsibility. (Mubarak et al. 2015, 110-113, Tiilikainen 2013, 175-177.)

I find this an important matter to take into account as a health care professional when dealing with Somali customers in the health care sector. Somali mothers are usually the ones, who take care of the child's matters, but in general many Somali women write and read poorly, or not at all and some are even illiterate (Castaneda et al. 2012, 54-55). In addition, many of the Somali women do not have any education. (Toivainen et al. 2012, 54-55)

Additionally, Mölsä and Tiilikainen (2007) emphasize in their study that Somali language has a strong oral tradition and Somalis use more verbal than written language (Mölsä & Tiilikainen 2007). Both of these aspects should be taken into account when dealing with Somali women in the health care sector for example, health care professionals should pay attention to the use of interpreters and verbal communication instead of written. It is good to take into consideration that important messages are always said verbally as well.

## 5.4 Improvements for the Finnish health care

In this section, the results from participants' opinions about the possible improvements for the health care and rehabilitation services are presented. After investigating how the Somali parents find the health care and rehabilitation services for their disabled chid in Finland, it was interesting to find out how they would improve the services. All the participants considered that Finnish health care and rehabilitation services for their disabled child are really good, but they also had some improvement ideas. The participants were asked questions relating to how the health care services for special needs children should be improved, and what kind of services and support would they wish and need more.

The opinion among most of the participants concerning the improvements in the disabled child's health care and rehabilitation services was to get more information. Getting more information was considered very important, especially among two of the participants. The participants considered that they do not have enough knowledge about the Finnish health care service system and all the possible services. The participants also pointed out that they do not have enough knowledge about the child's disability and children's neurological disorders and developmental delays generally.

In addition, two of the participants highlighted that these issues need more information among the Finnish Somalis. This finding is understandable because the disability health care is very poor in Somalia (Mölsä 2012.) Moreover, the cultural aspects were considered essential among the participants and some ideas for improvements concerning cultural matters also came out.

One of the participants was really worried about Somalis' low level of knowledge related to the children's developmental delays and neurological disorders. She emphasized that the general information about various children's developmental problems would be important for all the Somalis in Finland. The information should cover number of different developmental challenges, not just one particular disability. Getting more information would also help for the disabilities shameful stigma. As Mölsä's (2012) study presents, there are misunderstood believes which can cause disabilities (Mölsä 2012, 60-62). Due to the increased knowledge, also the understanding about the various problems could increase. Additionally, understanding about the rehabilitation would increase among the Somalis, which would be very important. On the other hand, when the health care professional gives information about these things, it is good to take into account that disability is always a culturally sensitive matter (Raghavan et al. 2007). One of the Somali mother described as follows:

> It is important to tell that if the child had problems for example, in language development or walking, she or he could be helped in various ways. Everything does not need to be coped, there is different help available.
>
> Informing is also important that immigrants would know that a child could get help, and rehab for various disabilities. It would be good if there were information events for the immigrants, and they were told that these kinds of children could be helped.

As described above, two of the participants emphasized that it would be important that the information events concerning the children's developmental problems and the Finnish health care system were arranged only for the immigrants. Among the participants it was considered that the common culture has an essential role especially in disabled children's health care issues. This is also in line with Raghavan et al. (2007) research, which found that disability is always culturally sensitive matter (Raghavan et al. 2007).

In addition, the peer support between the Finnish Somalis is considered very important among the participants in these kinds of situations. As mentioned earlier, the interpreter is considered very important for linguistic reasons, but it also strengthens the cultural cohesion. One of the participant commented:

> Peer support is very important, but if they are only Finnish people, it is not good it does not help.

Relating to the participants' ideas for improvement in the disabled child's health care and rehabilitation services, it was important to investigate what the best way for the health care professionals to give information to Somali parents could be. In addition, the purpose was to find out where and when the information should be given and also how to gather all the litigants was essential.

The participants, who wished more information from the health care professionals, suggested that the best way for giving the information is straight and honest talk. Verbal communication was considered definitely better than for example, written information documents. This is also in line with Alitolppa-Niitamo and Ali (2001) study, which showed that Somali culture has a very strong tradition of oral expression. Most of the Somalis listen to a spoken language rather than read. (Alitolppa-Niitamo & Ali 2001, 137-140.) According to the participants, the spokesperson's gender does not matter, but the important point is that there should be different professionals, such as therapists, teachers, doctors, etc. who give the information concerning the children's developmental issues.

In addition, the participants considered that it would be good if the information were given in different places, such as in children's clinics, day care centres, and schools. One of the Somali mothers suggested that the health care professionals should come there were the most of the Somali mothers spend their days such as, certain residential zones, and the children's playgrounds.

One of the participants pointed out that it would be essential to get information straight away when the child's diagnosis is given for example, in the hospital or if the child has a congenital disability then straight away after the child has been born. On the other hand, one of the Somali women emphasized that the information provided in advance is also important in order to prevent possible problems. She also alleges that the grapevine would bring the Somalis together and that is a natural way for Somalis. Two of the participants commented the following:

> If one day someone says that somewhere is talked about children's health- any mother would go take a look. The grapevine would bring the people together surely. The information could be given in the residential areas or children's playgrounds, which are full of mothers and children.
>
> It would be good to get information about the disease and the services in the beginning, as well as all the things that are possible to get. The best way is definitely straight talk and that things are told honestly. The information events could be in children's clinics, day care centres or at schools.

Also, according to the Somali interpreter, giving the right information about children's disabilities was considered important. It is essential that the health care professionals pay attention to where, when, and how the information is given. The interpreter emphasized that cultural issues need to be taken into account when dealing with Somalis:

> Information giving concerning these issues is really important. Information events could be held in those places where the majority of Somalis spend time, such as resident houses and club spaces. Often they are in seclusion. Jungle Drum is excellent and brings the right people together. I've seen some good information, but they are online and no one reads it from there. It needs to be used the way that works for them.

Two of the participants considered that there is no need for improving the disabled child's health care and rehabilitation services in Finland. Their proposals mainly concerned the disabled child's leisure activities and the family's everyday life. Even though they were asked to elaborate on the topic, they were not willing to clarify. Two of the Somali mothers described:

> It would be good if there were more something to do besides the school activity. It would be good to have more activities and hobbies for the child.
>
> It would be good if you could be more together with others.

According to the Somali culture specialist, health care processionals need to take the cultural matters into account. The specialist emphasized that it is important to inform Somali families about various matters such as the health care environment. The Somali culture specialist said the following:

> Healthcare professionals should be aware of cultural backgrounds, and also have discussion with families to find a common understanding. Somali families do not necessarily understand the diagnoses and prognoses and what they mean or the rehabilitation, implement tools and such. Verbal information is always important, only written information is not enough. Cultural sensitive communication is important and confidence is needed. For example, a Somali video material about the subject could be suitable. (Video footage of a Somalian family with a disabled child / youth and how their life is going)

# 6 Research process discussion

When I got interested in this topic and decided to conduct the study, I realized soon how difficult it was to get Somali parents who have a disabled child to participate in the interviews. When facing the challenges I still wanted to keep the chosen topic, but I did not set any exact amount for the needed participants. I consider that choosing the Somali immigrants for the study was good and interesting for a few reasons. Firstly, Somalis are one of the biggest immigration groups in Finland (Tilastokeskus 2015). Secondly, in Somali families both parents are usually Somalis, which is important to get an authentic view (Tiilikianen 2013). In addition, the Somali culture has long traditions, and the traditions have remained important also among the Finnish Somalis (Alitolppa-Niitamo & Ali 2001, 137-140).

Thirdly, I have some personal experiences of Somalis as clients in the health care sector and I have noticed differences between Somali and Finnish patients' towards for example, health care issues and disability. Due to this, Somali culture interests me personally because of its differences compared to Finnish culture. Additionally, it was also Hilma organization's wish to focus on Somalis. The purpose was to get both women and men's (mother and father's) opinions in order to see whether men and women have differences in the opinions

The participants' time being in Finland was not defined more specifically, which I find suitable in this study. Of course, the longer they have lived in Finland, the more likely it is to have more experiences of various services. According to Tuomi and Sarajärvi (2003), in qualitative research it is good that the participants have as much experience as possible about the research matter (Tuomi & Sarajärvi 2003, 87-88). Despite this I did not set any required time for being in Finland, because I did not want it to eliminate suitable participants, which were regardless only few.

The clear definition for the term disability was not essential in the study and therefore disability is not defined more specifically. I have used the "roof term" disability when generalising all the different disability forms. In the study, the child's disability can mean neurological special need, intellectual disability, physical disability or mixed diagnosis. More important than the specific disability definition were that the parents have experiences of the child's various health care and rehabilitation services. It was meaningful that the child has gotten some health care and rehabilitation, or had been in a special school or day care in Finland. If the child has gotten various treatments and therapies then also automatically the parents would have some prior experience about the child's disability services.

Similarly, the child's age was not clearly defined in the study. However, the child had to be on that form of age that he or she has used various health care and rehabilitation services in Finland. A new born child with a disability would not be suitable for the study, which purpose is to find out the kind of experiences the family has concerning the disabled child's health care and rehabilitation. For that reason concerning the interview, it was good the older the child was so that the parents had experienced as much as possible about the child’s different health care and rehabilitation services. Nevertheless, the child needed to be less than 18 years to be considered as a “child” in the Finnish health care.

Furthermore, the reason behind examining both the disabled child’s health care and rehabilitation in the study was due to the fact that the health care and rehabilitation are closely tied together. I consider that it is difficult to make a difference between disabled child’s health care and rehabilitation even for a native Finnish person and therefore it must be confusing for immigrants. For this reason the differentiation between health care and rehabilitation was not made in this study and I find it a good solution. Moreover, the purpose was to obtain information from parents' experiences of different health care and rehabilitation services, therefore the services were not purposely limited too precisely.

When planning the study, it was decided to use a Somali language interpreter in the interviews otherwise the participants’ language skills could have been a barrier in the interview. I find the use of an interpreter very important, because the questions were quite profound, and sensitive concerning the person’s situation and experiences. I considered that is highly important that the participants can use their mother tongue in this kind of situations. In addition, using the interpreter was also intended to reduce misunderstandings, because some of the health care words, and health care services might be difficult to understand in Finnish for Somalis.

On the other hand, there are some disadvantages when using an interpreter. The use of an interpreter may impair the reliability, when the response passes through a third person. Also, ethical issues must be considered; not all necessarily want to talk about sensitive subjects with an interpreter. However, in this case the interpreters’ same cultural background might have been a positive thing, and helped the interview situations in many ways. In addition, the interpreter was familiar to me and therefore we had a common understanding of the issues. Concerning the reliability of the translations of the interviews, I have put some examples on the appendix (8).

When I chose to use only a small sample size of the data, it was clear to me that the results of this study would only reflect the views and perceptions of these particular Somali parents. Therefore, when considering the validity of the study, I would like to emphasize that the goal of this study is not to make any generalizations and neither was the initial goal of the study. Concerning the validity of the study, I did not have any “new generation’s Somalis” and all of the participants were not born and raised in Finland. Somalis born in Finland are usually more educated and open-minded compared to the Somalis who have immigrated to Finland. Younger Somalis and Somalis born in Finland probably view disabilities differently than the older generation, because they have more education and they have used the Finnish health care services already at a young age. I think that could be an interesting view to take into account when considering ideas for further studies.

The thesis process has been very interesting and I have learned a lot. After writing this thesis, I feel that I have gained a lot of useful knowledge that I can employ in my own profession. Because the world is constantly changing and becoming more multicultural, I think that it is important that health care professionals will learn and understand more about different cultures and customs. I have gained more cultural knowledge and understanding towards one of the biggest foreign cultures in Finland. I got familiar with how the attitudes towards disabilities can vary between Finnish and Somali cultures. I have realised that cultural differences towards disabilities are important to take into account when dealing with Somali customers in health care, which I find essential as a children's occupational therapist. In addition, to my increasing knowledge, the study will benefit my current job and the workplace's needs as well.

In the Applied Sciences Universities, the purpose of the master's thesis is to gain practical knowledge and be applicable for working life. For this reason, the purpose of this study was to provide solutions for current and concrete issues. The obtained results are also very useful for the Hilma organization's needs especially in how the organisation can help the Somali parents in need. The cooperation with Hilma organisation was effective and supportive from the beginning. The final study will be published on the Hilma's Internet page.

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# Appendices

## Appendix 1: Interview invitation

Hi!

Are you a Somali background mother or father with a child who has intellectual disability or special needs? I am interested to hear your opinion and experiences of your child's care and rehabilitation in Finland.

I am children's occupational therapist and studying Global Development and Management in Health Care – Master's degree in Laurea University of Applied Sciences. I am currently doing my thesis which purpose is to improve services of immigrant background children with special needs. The thesis is carried out together with Hilma- The support Centre for Immigrants Persons with Disabilities.

I would like you to participate in an individual interview, and answer questions about your experiences concerning your child's health care services. In the interview, the information provided will be treated confidentially and the interviewees' identity will stay anonymous. The interview takes about an hour and can take place according to your wishes. There is a Somali interpreter in the interviews.

Thank you in advance!

Best Regards,

Jenny Starck

Registration and information enquiries: jenny.starck@student.laurea.fi
johanna.warius.tukikeskushilma.fi

Appendix 2: Interview invitation in Somali language

Codsi waraysi ku socda reeraha somalia ka soo jeeda ee haysta dhallaan xanuunsanaya ama u baahan taakuleyn dheerada

Assalaamu Calaykum!

Ma tahay hooyo ama aabo kasoo jeeda Somalia oo reerka ugu jiraan ilmo jismiyan ama maskaxiyan u xanuunsanaya una baahan taakuleyn gaar ah? Waxaan rabi lahaa inaan maqlo fikraddaad ka qabtid saacidaadda ama caawimada aad kala kulantay wadanka Finland.

Waxaan ahay *toimintaterapeutti* la shaqaysa dhallaanka, waxaanan dhigtaa jaamacada Laurea takhasuskayguna waa Global Development and Management in Health Care oo aan ka diyaarinayo darajada labaad ee jaamacada. Waxaan diyaarinayaa buugga qalinjabinta oo aan ku baadhayo sida loo kobcin lahaa caawimada la siiyo carruurta uu nasabkoodu kasoo jeedo wadan kale. Baadhitaankan waxaan la hir galinayaa haayada Hilma.

Waxaan rajayn lahaa inaad ka soo qayb qaadatid waraysi shakhsiyan ah, oo aynu ka wada hadlayno waxaad ka dareensantahay ama kala kulantay caawimada caafimaad ee uu ubadkaagu helay ama helo. Arrimaha ka soo baxa wada hadalkan waxaa loola dhaqmi doonaa si amaan ah oo ka qaybgalkaagu ama magacaaga iyo wixii la hal maala kama muuqan doono buugga baadhitaanka. Waraysigu wuxuu socon doonaa illaa saacad. Waxaa lagu qaban karaa meeshaad adigu dooratid. Turjubaan af Somali ahna wuu ila socon doonaa.

Aad baad ugu mahadsantahay caawimadaada!

Jenny Starck

Is diwaangelinta iyo wixii macluumaad dheeraad ah waxaad kala xidhiidhi kartaa:

jenny.starck@student.laurea.fi

johanna.warius@tukikeskushilma.fi

Appendix 3: Interview questions for the Somali parents

## Interview Questions for the Somali parents:

### The interviewee's background information:

- How long have you lived in Finland?
- How well do you know Finnish language?
  (Self-assessment: none/ some / moderately / well / very well)
- Where do you live? / Are the experiences conserning the child's health and rehabilitation services from the same place where you live now?
- Tell about your family:
  Are you married?
  How many children do you have? How old are the children?
  Which of the children have special needs?

### Child's background information:

- Tell about the child with special needs:
  - What kind of special needs does he or she have?
- When did you realize something unusual in your child's development?
- Does you child been diagnosed?
  - When and where the diagnosis was given?
- Where was your child's special needs first recognized: in your family, or in some other place, such as the child health care centre or day-care etc.?

### Child care and rehabilitation experiences / the cultural aspects:

- What kind of treatment and rehabilitation has your child received?
  For example, various therapies, kindergarten / school support
- Have you received any other help and assistance related to the special needs of your child?
  For instance, guidance, peer support, adaptation training, financial support, taxi service, etc.
- Does your child currently get any kind of support in kindergarten or school?
  For example, support in specific group or personal assistance, etc.

- Do you agree with your child’s care and rehabilitation plans with health care professionals?
- Are you aware of the different forms of therapies?
  For example, if the child gets occupational therapy, do you know what it means in your child's case?
- Do you feel that the rehabilitation has helped your child? How?
- How are your child’s special needs viewed in your culture?

**Service experiences / service improvement:**

- What kind of service have you received related to your childcare and rehabilitation?
- Have you been satisfied with the service?
- Have you received support when needed?
- Have you been satisfied with any particular professional/ professionals involved?
- Do you feel that language has caused any problems or affected the matters of your child’s care and rehabilitation?
- Have you received a Somali language interpreter when necessary?
- Do you think there has been anything unnecessary concerning your child’s health care support?
- Have you used all services provided?
  If not, which services have you not used?
- What kind of negative experiences do you have related to your child’s care and rehabilitation services?
- How the healthcare professionals have taken cultural matters into account?

- What kind of support would you have wished for? What would you have liked or needed more?
- How should the treatment services for special needs children be improved?
- What other services would you like to have for your child?

**Else:**

- Would you like to comment on anything?

Appendix 4: Interview questions for the interpreter

## Interview Questions for the interpreter:

### The cultural vision:

- What do you think could be the reasons why getting interviewees was so difficult?
- How did you motivate the participants?
- Those who did not participate, did they name any reasons for they choice?
- What kind of effect may the interviewer's cultural background have on the interviewee?
- What are the challenges in using an interpreter in such context?
- Not a single man (father) participated in the interview, what do you think could be the reasons for this?

- What kind of experience do you have with disabled children in Somali culture?
- What kinds of attitudes are there towards disabled people in Somali culture?
  - Are there differences in attitudes between men and women?
  - Are there differences between generations?

- As a Somali - what do you think about the Finnish health care services?
- What kinds of conflicts have you encountered? Can you describe any usual problem situations between Finns and Somalis?
- How are cultural aspects taken into account in the Finnish health care system? For example, the use of interpreters, etc.

- How could the health care services be developed concerning Somalis with disabled children?

- Would you like to comment on anything else?

Appendix 5: Interview questions for the Somali culture specialist

## Interview questions for the Somali culture specialist:

- What kind of experience do you have in dealing with Somalis / knowledge of the culture?

## The cultural vision:

- What do you think could be the reasons why getting interviewees was so difficult?
- Not a single man (father) participated in the interview, what do you think could be the reasons for this?

- What kind of effect may the interviewer's cultural background have on the interviewee?
- What are the challenges in using an interpreter in such context?

- What kinds of attitudes are there towards disabled people in Somali culture?
- Are there differences in attitudes between men and women?
- Are there differences between generations?

## The development of health services:

- How the health care professionals should take cultural aspects into account?
- How could the health care services be developed concerning Somalis with disabled children?

- Would you like to comment on anything else?

Appendix 6: Consent form

Permission and consent form for an interview and the use of the interview results in the study:

I am children's occupational therapist and studying Global Development and Management in Health Care – Master's degree in Laurea University of Applied Sciences. I am currently doing my thesis which purpose is to improve services of immigrant background children with special needs. The thesis is carried out together with Hilma- The support Centre for Immigrants Persons with Disabilities.

In the interview, your experiences concerning your mentally handicapped child's health care and rehabilitation services in Finland are examined.
The interviews are recorded for later analysis of the data. After the research is completed, the recordings will be destroyed. For your privacy, you are identity will stay anonymous. There will be a Somali language interpreter in the interviews who is also entitled to full confidentiality. The consent is valid until further notice, but the approval may be withdrawn at any time.

Best Regards,
Jenny Starck

I give my permission for the interview and use of the results in the study.

The interviewed:

________________________________________
Place and time

________________________________________
Signature and print name

# Appendix 7: Interpreter's confidentiality agreement

## Interpreter's confidentiality agreement:

The interpreter has full confidentiality towards information obtained in the interviews. The interpreter does not misuse any knowledge she has gotten from the interviews.

The interpreter:

I agree to keep all information provided in the interviews in strict confidence.
I understand that the confidentiality continues after the interviews have been completed.

________________________________________________

Place and time

________________________________________________

Signature and print name

## Appendix 8: Transaltion examples from the interviews

### Example 1: The Somali parent:

“Suomen systeemi on erittäin hyvä. Olen hyvin tyytyväinen kaikista palveluista joita olen saanut ja kaikki palvelut ovat olleet erittäin hyviä.”

“The Finnish system is very good. I am very happy with all the services I have gotten, and all the services have been great.”

### Example 2: The Somali interpreter:

“Tiedottaminen ja informaation antaminen näistä asioista on todella tärkeää. Tiedotustilaisuuksia voisi olla niissä paikoissa missä suurin osa somaleista viettää aikaa, kuten esim. asukastalot ja kerhotilat. Usein he ovat omissa oloissaan. Viidakkorumpu toimii erinomaisesti ja tuo asianosaiset paikalle. Mä oon nähnyt jotain hyviä informaatioita mutta ne on netissä eikä sieltä lue kukaan. Pitää ottaa se tapa käyttöön mikä toimii heille.”

“Information giving concerning these issues are really important. Information events could be held in those places where the majority of Somalis spend time, such as residenthouses and clubspaces. Often they are in seclusion. Jungle Drum is excellent and brings the right people together. I've seen some good information, but they are online and no one reads it from there. It needs to be used the way that works for them.”

### Example 3: The Somali parent:

“On tärkeä kertoa, että jos esim. lapsella on ongelmia kielen kehityskessä tai kävelemisessä häntä voidaan auttaa eri tavoin. Kaikkea ei tarvitse kestää vaan erilaista apua on tarjolla. “

“It is important to tell that if the child had problems for example, in language development or walking, she or he could be helped in various ways. Everything does not need to be coped, there is different help available.”

### Example 4: The Somali culture specialist:

”Vammaisuus koetaan herkästi häpeällisenä, ja vammaiset lapset, varsinkin tytöt saatetaan pitää kotona piilossa. Somaliassa usein ajatellaan, että vammaisuuden taustalla ovat esim. pahat henget tai kirous, jolloin olennaista hoidossa on näiden henkien tai kirousten kartoittaminen- ei niinkään kuntoutus.”

“Disability is considered highly shameful, and children with disabilities, especially girls may be kept hidden at home. In Somalia it is often thought that the background of disability is either evil spirits or a curse, in which case the treatment should drive these spirits away- rather than rehabilitation.”

# Appendix 9: Cooperation agreement with Hilma organisation

## YHTEISTYÖSOPIMUS

Laurea -yamk:n opiskelija Jenny Starck tekee yhteistyössä Vammaisten maahanmuuttajien tukikeskus Hilman kanssa opinnäytetyönsä Global Development and Management in Health Care - maisterintutkintoa varten.

Työn aiheena on somalitaustaisten erityislasten hoito- ja kuntoutuspalvelut ja niiden kehittäminen. Työ toteutetaan tutkimushaastatteluna. Tukikeskus Hilman koordinaattori tarjoaa asiantuntemustaan, sekä maksaa tulkkina toimineelle henkilölle korvauksen hänen avustaan. Työ julkaistaan Tukikeskus Hilman kotisivuilla sen valmistuttua.

Koordinaattori Johanna Warius

Opinnäytetyön tekijä Jenny Starck

Vammaisten maahanmuuttajien tukikeskus Hilma
Vammaisfoorumi ry

Marjaniementie 74, 00930 Helsinki

E-mail: info@tukikeskushilma.fi
Puhelin: +358 (0) 50 300 2501

Hilma
vammaisten maahanmuuttajien tukikeskus