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**THE WELLBEING OF IMMIGRANT PARENTS WITH CHILDREN WITH AUTISM  
SPECTRUM DISORDER**

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## ABSTRACT

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Taking care of children can have an influence on parents' wellbeing and the same applies to having a child with an autism spectrum disorder (ASD). The aim of this study was to gain an understanding of the challenges immigrant parents face in everyday life of taking care of their child with ASD and how it affects their wellbeing. Five immigrant parents with children with autism spectrum disorder in Finland were interviewed and their narratives were analysed by using qualitative content analysis.

The results show that immigrant parents' experience of having a child with ASD has an influence on their wellbeing both positively and negatively. Professionals and the municipality provide avenues for better services that promote a positive impact on the wellbeing of the immigrant parents whilst cultural diversity, language and lack of confidence also affect them negatively.

Again, the study's finding revealed that immigrant parents with children with ASD face challenges such as stress, maintaining social relationships, and diversity in cultural beliefs. Additionally, the study further shows that having a daily routine, acquiring knowledge on ASD, and receiving support from the social and health services were mechanisms that help them deal with the situation.

Many websites for ASD have adequate information about the condition, the process in diagnosis, rehabilitation, and how to cope with the child's functional development daily. However, the focus is more on the child with ASD and not the parents who will cater for the child's needs and functionality. Therefore, professionals in this field need to provide culturally competent care and encourage immigrant parents to out voice their expectations and discomfort.

The research urges further studies on this subject to support the wellbeing of immigrant parents with children with autism spectrum disorder.

**Keywords:** Wellbeing, Autism Spectrum Disorder, Immigrant Parent

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# 1 INTRODUCTION

This thesis seeks to explore the wellbeing of immigrant parents with children with autism spectrum disorder (ASD). Autism Spectrum disorders can occur from birth, and on many multiple levels, and immigrant parents are sometimes left with no or little information about how to take care of their child with ASD. More information, and orientation are needed to educate immigrant parents on how to take care of their children with ASD. Again, consideration of the needs and strengths of the family is needed as a support for the immigrant parents in order to improve their wellbeing (Baker & Milivojevic, 2013).

This study adopted a qualitative research approach using semi-structured questions for interviews to explore the experiences of immigrant parents with ASD children.

We realized during our work practice with immigrants that, most immigrant parents are afraid to seek help because of the possibility that their children might be taken away from them. This thesis aims at highlighting the challenges immigrant parents face in everyday life in taking care of their children with ASD and how it affects their wellbeing.

Research concurs that immigrant parents face challenges in integrating into foreign cultures and their challenges can double when there is a child with ASD involved (Arfa et al., 2020). There has been debate over the years about the experiences of parents taking care of their children with ASD and how it might affect their wellbeing. However, the information available to parents on ASD and how to take care of their wellbeing is less than the studies done on the child with ASD.

## 2 BACKGROUND

The immigrant population in Finland has grown over the years. It started in early 1990 when people fled their countries due to war and persecution to seek refuge in Finland. Immigrant parents in this study are the biological birth mothers and fathers who are raising children with autism spectrum disorder (ASD) who were born in Finland or in abroad. According to statistics from Autism Finland and different studies on ASD (Lehti et al., 2018; Autism Europe; Giallo et al., 2011), the number of diagnoses of ASD is growing with approximately one percent of the population in Finland having ASD (Autism Finland).

Rocha-Trindade (1995) explains ‘migration as a history of mankind having a constant phenomenon which has fluctuated in the last decades due to globalization, nationalization, economic, social development and technological innovation’ (Rhodes, 2005 p. 172). Finland started welcoming immigrants in the 1990s and has since become a multicultural country where people immigrate and emigrate for reasons such as work, family, study, or shelter. The number of immigrants arriving in Finland between 2010-2020 increased from 26,000 to almost 35,000 per year with the highest record seen in 2016 with 34,905 (Statistic Finland). Finland has therefore put in a mechanism to ensure that the society accommodates multilingualism and cultural diversity through the integration programmes (Vaestöliito.fi).

A significant growing percentage of immigrant parents in Finland have children with autism spectrum disorder (ASD). However, the field of research has conducted little study on the wellbeing of immigrant parents with children with autism spectrum disorder (Autism Finland; Arfa et al., 2020). Most research done in Finland on autism spectrum disorder is based on case-control studies which usually focus on the child with ASD (Lehti et al., 2018).

According to Lathe, (2006), there has been an assumption that the diagnosis of ASD is related to children or adolescents, which is not the case as ASD is a life-long syndrome that causes individual and varying disabilities (Autism Finland; Lathe, 2006). Autism is more common than usually thought. Various studies have demonstrated that, one out of a hundred people have autism globally (Autism Europe).

This requires support and care from loved ones in handling the daily activities of people with an autism spectrum disorder.

Observations by parent, guardian, child health clinic (neuvola), or school health care of a suspicion of ASD show that, ASD usually occurs when a child is between 1.5 to 2.5 years old. Symptoms that are common for referring a child for further examination include difficulties in making contact with others and delay in speech development (Hospital District of Helsinki and Uusimaa).

ASD is a permanent trait. However, having good support from the environment with rehabilitation can enhance the wellbeing and cope of a person with ASD. Parents are one support mechanism that needs to have adequate information to support the ability function of the child with ASD. The percentage of the population with ASD includes children of immigrant parents who have become a significant part of Finnish society. (Autism Finland).

However, immigrant parents sometimes face challenges in settling in their new environment which has been supported by several studies (Arfa et al., 2020; Lehti et al., 2018; Giallo et al., 2011). These challenges include the language barrier, difficulty in adapting to the host country's culture, unemployment, and so on. Adapting to their new environment and caring for a child can bring its own challenges which can influence the wellbeing of the immigrant parent (Arfa et al., 2020).

## 2.1 Previous Studies

There has been quite several research done on the experiences of an immigrant parent having a child with ASD and why early support from professionals is needed for their understanding and adaptation (Pozo & Sarria, 2015; Arfa et al., 2020; Giallo et al., 2011). These previous studies relate to our study on the wellbeing of immigrant parent with children with ASD.

Lin, Yu, and Harwood (2012) used 2007 national survey in Norway of children's health to compare children with ASD from immigrant families and non-immigrant

families. Children with ASD from immigrant families were more likely to lack care and support from health care. This can be a burden to families who do not have enough resources to care for their ASD child. Apart from the challenges immigrant parents face in navigating in the foreign society, they are as well faced with the challenge of caring for a child with ASD. These challenges and experiences have both positive and negative impacts on their wellbeing (Arfa et al., 2020).

Pozo and Sarria (2015), conducted a study on 102 Spanish parents with children with ASD, with the aim of examining parental wellbeing regarding stress, anxiety, depression, and psychological wellbeing. The children with ASD were grouped into three categories namely adults, adolescents, and young. The results indicated that although parents stress and psychological wellbeing levels had similarities with all the three categories, depression and anxiety were seen in lower levels in parents of adolescents or adults compared with parents of younger children with ASD. The challenges and wellbeing can be influenced in all stages of the parents with a child with ASD (Pozo & Sarria, 2015).

Legg and Tickle (2019), 'reviewed 11 articles by systematically identifying, appraising, and synthesizing qualitative research concerning UK parents' experience of their children receiving diagnoses of ASD. Three third-order concepts were developed which involved emotional needs, information needs, and relational needs which relate to parents' needs as they pass through the process of adjusting to the diagnoses of ASD. There were variations in the parents' experiences of assessment and diagnoses. However, their needs were evident across the course of the process. In conclusion, the researchers emphasized the need for consideration of parents' emotional needs, provision of information to support understanding, and having strong relations with professionals. Building strong relationships with professionals is one of the challenges that immigrant parents face as some professionals are not culturally sensitive to the diverse needs of the immigrant parent (Arfa et al., 2020).

Green et al. (2020) noted 'that, research has shown increased mental health difficulties among parents of children with autism compared to other parents. However, factors that influence and promote wellbeing remain poorly considered. The study examined 136 parents of young children with autism with mental health been predicted by both traits negative emotionality whiles wellbeing been predicted by parent factors alone

including trait extraversion and mindfulness. They concluded that wellbeing was predicted by a modifiable parent characteristic which is mindfulness and suggests the potential for early support to bring direct benefits for parents in the context of raising a young child with ASD' (Green et al., 2020).

Millau et al. (2019), 'argues that to date only a few studies have contrasted the experiences of immigrant and native families. The researchers conducted the study of 104 immigrant and Canadian-born mothers and fathers using the Beach Center FQOL (Family Quality of Life) Scale following the child's ASD diagnosis and the provided ratings of perceived support. The result was that, immigrant families were less satisfied with their FQOL than Canadian-born parents. However, no gender difference was observed. Another finding was that fewer immigrant families reported having access to external support than Canadian families. In conclusion, the researchers noted that parents may benefit from different services and thus it is important to develop programs that take into consideration parents' gender and cultural background whilst providing means of developing external support networks. Many people may experience the shock of their child's diagnosis of ASD, but it can be compounded among immigrant parents due to lack of familiarity, language barrier, and different beliefs regarding ASD (Klinger et al. 2009; Magana et al. 2013). It is vital to have services that provide adequate support to these immigrant parents and the importance of professionals understanding the diversity of culture (Millau et al. 2019).

Parents face challenges raising children which include fatigue, and poor quality of sleep in the early stages of the child's development. However, some immigrant parents with children with ASD may be faced with high levels of stress, anxiety, and depression which might influence their parenting experience (Giallo et al., 2011).

Lindsay et al. (2012), used qualitative in-depth interviews and focus groups to understand the experiences of service providers working with immigrant families having a child with a disability. The experiences included challenges in language and communication, lack of training in providing culturally sensitive care, discrepancies in the understanding of the disability between healthcare providers and the immigrant parents, building rapport, and helping parents to advocate for themselves and their children. They concluded that more training opportunities are needed for enhancing culturally sensitive care.



These previous studies have similarities on the challenges that immigrant parents with children with ASD face such as stress, anxiety, cultural difference, and how it affects their wellbeing. The everyday experiences can have both positive and negative impacts on their wellbeing because it is subjective in nature and thus can be experienced differently. The wellbeing of a parent is essential for every child's development and growth (Arfa et al., 2020).

## 2.2 Work Life Partner

Familia ry is the work life partner for this thesis. Familia ry is a non-governmental organization (NGO) that has projects which are organized to fill the gaps in the society about services and make services known to people. Their projects offer education to participants about available services and train diverse families to enable them to integrate well into Finnish society.

Their projects are funded by Funding Centre for Social Welfare and Health Organization (STEA). Their projects aim to provide information regarding the needs of diverse families. This study will provide them with relevant information on the topic and understand why some immigrant parents react differently with their children, especially with children with ASD. Again, it can help the work life partner to create the right platform such as workshops, seminars, peer groups, and support to these immigrant parents with children with ASD.

The work life partner helped in editing and modifying our work in the thesis process. The work life partner can use this study as a basis for further project development for those in diverse families who face marginalization in society. (Familia ry).

### 3 KEY CONCEPTS

This chapter focus on the key concepts used in this study, the definitions of these key concepts with respect to the wellbeing of immigrant parent with children with ASD.

#### 3.1 Autism Spectrum Disorder

Autism is a disorder that comes from birth or at a very early stage during development that affects essential human behaviours such as social interaction, the ability to communicate on its own ideas, feelings, imagination, and the ability to make friends or keep relationships with others. It has life-long effects on how children learn to socialize with others, taking care of themselves and participating in the community.’ (Educational Interventions for Children with Autism Committee 2001, 11).

Autism spectrum disorder (ASD) is a dysfunctional developmental problem involving challenges in social interaction, speech, nonverbal communication, restricted, repetitive, and inflexible behaviours (Sharp et al., 2013). Autism Spectrum Disorder (ASD) is an umbrella term used to describe a range of neurodevelopmental conditions with shared core symptomology of impaired social interaction and communication abilities and stereotyped or restricted patterns of activities, interests, and behaviours which significantly impact the individual functioning (Legg & Tickle, 2019).

Under WHO’s International Classification of Diseases (ICD). Diagnoses are ‘Autism (F84.0), Asperger Syndrome (F84.5), Rett’s Syndrome (F84.2), Childhood Disintegrative Disorder (F84.3), and Atypical Autism (F84.1)’. The diagnoses of ASD will be replaced with ICD-11 classification updates generalized within the category of autism which WHO has plans to implement as of the beginning of 2022 (Autism, Europe). This research study will focus on the average level of ASD and not an in-depth as the aim is to explore the wellbeing of the immigrant parents taking care of the child with ASD (Autism, Finland).

According to Lathe (2006), ASD is a neurodevelopmental disorder that hinders the ability to communicate, socialize, sense, and experience the world. Furthermore,

autism disorder is a complex lifelong condition and can be associated with general medical or genetic conditions. Some of the individuals with ASD will be able to manage their everyday tasks, while others will need special support for the rest of their lives. Moreover, Lathe (2006, 35) explains that it is very difficult to adopt uniform diagnostic instruments and methods due to the wide differences in individuals with autism.

### 3.2 Wellbeing

Wellbeing is a positive outcome that enhances our living and is important for people and for the community because it helps and promotes peoples' living. When people are in good living conditions, they can do every other activity in their lives. Good living conditions are the main fundamentals to wellbeing (Arfa et al., 2020).

Wellbeing is generally in three categories. The first category is physical wellbeing which involves exercising, sleeping, and habits. The second category is psychological wellbeing which has to do with the ability to handle stress and the ability to handle daily life with a positive attitude. The third category is the social aspect which talks about the mentality to stay positive and supportive. (New Economic Foundation,2012).

Wellbeing can be defined as a combination of feeling good and functioning well, with experiences of positive emotions, for example happiness and satisfaction, the progress of someone's potential. Having a sense of purpose and encountering positive relationships. These conditions allow the individual, or population to develop and thrive if they are sustainable. Wellbeing is like positive mental health. According to World Health Organization, mental health is “a state of wellbeing in which an individual realizes his or her own abilities, capabilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community.” (World Health Organization, 2001).

Wellbeing connects with success in many ways like in professional, personal, and interpersonal levels. It helps individuals to create greater productivity in everyday life activities like the example in the workplace, family routine, etc. It exhibits effectiveness in learning, increasing creativity, and more in prosocial behaviors, and

in good connection in relationships. Wellbeing brings better outcomes regarding physical health, better life satisfaction, and longer life span (Ruggeri et al., 2021).

Parents often make mistakes of only focusing on the wellbeing of their children and not their own wellbeing. Parenting can be demanding and when coupled with having a child with ASD might be more demanding, that will need more physical and emotional energy (Arfa et al.,2020).

If parents can handle their wellbeing, they will be less stressed or feel less exhausted. Handling stress is more difficult when the wellbeing is not balanced. For example, psychological wellbeing is when people express and experience positive emotions and feelings of happiness. Cooper, (2011) believes that improving a family's wellbeing brings a wide range of benefits to them as individual families and the wider society. The extent of parents' wellbeing can be seen in how they take care of their children. (Cooper, 2011 p.51).

According to World Health Organization, wellbeing does not indicate sickness or diseases rather it indicates a good physical, social being, and mental health (Kim, 2012). In other words, it can be described as a positive result for an individual, society, environment, and so on. Wellbeing is connected to the experiences of health, happiness, and prosperity. It includes good mental health and life satisfaction. It is also linked to the inner state including physical and psychological health. Studying and finding the indicators of people's total wellbeing is however practically challenging as it is not only related to certain small dimensions. (Mental Health Foundation, 2015).

Nursing a child with ASD influences many core areas of the parent's life which has an effect on parent`s wellbeing emotionally and mentally. The child with ASD is not the only one that goes through challenges, struggles, anxieties, and difficulties. Many a time, their parents are even more worried for their children, because watching their children go through this journey is not always easy for parents, is an emotional struggle for them and most at times they worry too much and forget to consider that their own wellbeing is also important and needs to be taken care of. Emotions can lead some parents to feel guilty and think they are responsible for their child's condition, and those having high hopes towards perfection might possess feelings of disappointment in their child needing extra support (Volkmar & Wiesner, 2009 p.552).

Research (Arfa et al., 2020; Rudiger, & Spencer, 2003; Yoder et al., 2010) has strong evidence that raising a child is uniquely rewarding and challenging sometimes for parents, but raising a child with ASD is more challenging, demanding, information and more learning which lead to high stress of the parents and breakdown of wellbeing. Understanding factors that contribute to parental wellbeing is of utmost importance. Some studies have also indicated that parenting a child with ASD may have an impact on the parents' health and wellbeing because of the given multiple roles.

Vernon (2008 p.45) defines 'wellbeing as psychological growth as well as physical welfare relating to health, contentment and flourishing'. The author further explained that wellbeing has no definite definition as it can be subjective for every individual. The experiences of people may vary and thus influence the way they perceive their wellbeing. Immigrant parents' experience with navigating through the host country can influence how they perceive their wellbeing in terms of taking care of their child with ASD.

As an immigrant, there are other issues that can contribute to this, family and financial problems. Parents of children with ASD can experience a deterioration in their wellbeing through stress and emotional breakdown because they focus more on the child and less on themselves. Thus, it is observed that these can lead to other aspects of struggles, such as economic, environmental, and effect in social living. One example is cultural diversity and flexibility, which is understood as the ability of culture to maintain and develop cultural identity, knowledge, and practices (Arfa et al., 2020).

### 3.3 Immigrant Parents with Children with ASD

Migration comes in various ways with people moving from one country to another to settle elsewhere other than their own home country. On the other hand, Immigrant parents are usually born abroad living currently in another country (Gomez, 2015). Immigrants in Finland consist of persons born abroad, foreign citizens, foreign-language speakers, and persons with foreign backgrounds (Statistics Finland). When people migrate to a new country, firstly they face challenges trying to adapt to the system and the society including the culture. Integration also means having equal

rights to participate in all aspects within the society but giving special importance to maintaining one's own culture and language. Conversely, immigrant parents integrate into the new society with their children amid the challenges (Rudiger, & Spencer,2003).

Migration can be simply defined as crossing of border to an established location or place whereby one or more persons thus referred to an immigrant who are involved in a change of residence. For example, it could be a family migrating together, or one migrating to join the other. Migrating to another country has its own psychological wellbeing challenges that might be doubled in caring for a child with ASD despite the influence on happiness on most immigrant parents. Reasons for immigrant parent's migration include for better life, lack of jobs in their home country or sources of income, famine, or poor educational standards, and so on. (Rudiger, & Spencer,2003).

According to Arfa et al. (2020), immigrant families are systemically underrepresented in international studies of children with disabilities. Immigrant parents face a lot of challenges not only limited to the language barrier but also to different cultural expectations regarding seeking help and ethnic diversity that some professionals may not be aware of its implication (Arfa et al., 2020).

Parenting is a complex and intricate process that varies from one society to another. According to Yoder et al, (2010, p4), the culture you live in and the values you hold will be crucial in helping you determine what constitutes good parenting. There is no major way or rule that works equally when parenting as well as when the parenting journey involves a child with ASD. However, as parents exercise their rights and duties care must be taken to ensure the child's rights are observed for their protection as well as wellbeing (United Nations).

In Finland for example, children's interests and opinions are to be heard in all matters concerning them. The constitution stipulates that, children must be offered equal individual treatment as well as have an influence on issues that concern them (Child welfare Act). Raising children is the most lovely and challenging activity of adulthood. According to Deater-Deckard, (2004, p41-43), the transition to parenthood can be joyful, exciting, and stressful. The child comes into the world firstly by depending on his parents for survival and wellbeing. Same goes for a child with ASD. It is a joyful

thing to be a parent but also parenting can be stressful if wellbeing has been mismanaged (Yoder et al.,2010). Immigrant parents are not spared with the stressful challenges faced by parenting a child with ASD.

#### 4. PURPOSE AND AIM OF THE THESIS

Our aim in this thesis is to highlight the challenges immigrant parents face in everyday life of taking care of their child with ASD and how it affects their wellbeing. Our research questions were:

1. What type of challenges do immigrant parents experience with having a child with ASD?
2. How do the experiences of immigrant parents with children with ASD impact their lives?
3. What support does immigrant parents with children with ASD need in their everyday lives?

The aim of the thesis is not to focus on ASD, and its causes, symptoms, or treatment but on the wellbeing of immigrant parents with children with ASD. It is important to know and understand when to rest and how to deal with stress, using different mechanisms. Therefore, the wellbeing of parents with ASD children should be considered important.

The study hopes to help the work life partner to have relevant information about the study topic and help them to create awareness of the important fact about maintaining wellbeing, and the ability in building resilience to manage everyday life which is limited on the platform of some organizations that provide information about ASD in Finland specially to people from immigrant backgrounds. Also, the study will help the work life partner to know what further guidance could be given to support these immigrant parents (Autism Finland).



## 5. METHODOLOGY

The study used qualitative content analysis that was carried out with a semi-structured questions and using a one-on-one online interview approach. Research methodology is a 'way to systematically solve the research problem' stated in this study (Kothari, 2004). Qualitative research approach involves descriptive and non-numerical data such as audio recording, photos, videos, and texts. (Silverman 2005).

The work life partner was consulted before collecting data for the analysis. Research methods are the ways or methods used in performing research operations. The methods include the collection of data, techniques used to establish relationships between the data, and the methods used to evaluate the accuracy of the results obtained (Kothari, 2004).

The study explored the experiences and challenges of some immigrant parents with children with ASD and how it affects their wellbeing. As the study aims to understand the wellbeing of immigrant parents with children with ASD by looking at the challenges they face. The descriptions from their experiences would help to answer the research question. We listened to the narratives of immigrant parents with children with ASD to address the situation. We used the research methodology to find answers to our research questions.

A qualitative content analysis was chosen for this study to provide a holistic understanding of some social and human phenomena in the participants' lives. Qualitative methods were utilized in this research for the purpose of understanding immigrant parents' challenges and experiences with having a child with ASD. Experiences, attitudes, and behaviours are phenomena that allow participants to explain how, why, or what they were thinking, feeling, and experiencing at a certain time (Kothari, 2004). This emphasizes the experience of individuals as well as provides a meaningful understanding of them (Leavy, 2017).

The qualitative content analysis aims at generating meaning through the building of knowledge. A qualitative content analysis was appropriate for this study as it seeks to explore and describe human experiences (Leavy, 2017). This method allowed us to listen to what the participants said through questioning. Since the participants were the

ones having the experience, they became a source of knowledge for the study (Auerbach & Silverstein, 2003).

### 5.1 Data collection

This study used semi-structured interviews questions to enhance a wide range of possibilities and flexibility for the participants. Interviews were conducted using open-ended questions to generate, build meaning and seek understanding in the experiences of participants.

Participants were recruited through the work life partner (see Appendix 2). The recruitment of participants began immediately after the thesis proposal was accepted and the work life partner signed the thesis agreement. Emails were sent to participants followed by the consent form before the interview was conducted (Kothari, 2004).

The structure of the questions provided adequate space for the interviewee to offer more relevant information to the study (see Appendix 3). The semi-structured interview questions method helped us ‘pay attention to lived experiences of the participants during the interview (Leavy, 2017). The research questions comprise the literature review, thesis supervisor’s review, and the review of the work-life partners in ensuring well-formulated questions in terms of clarity, bias-free language, and openness (Kothari, 2004).

In other to accomplish the aim of the study, the sampling and recruitment were conducted by the work life partner and the researchers in this thesis. The work-life partner did the publication of the recruitment on their various social media platforms such as Instagram, Facebook, and WhatsApp to enable prospective individuals to participate in the study. The criteria were to look for immigrant parents with children with ASD who were willing to narrate and provide us with their experiences to the study topic.

The initial sampling plan was based on convenience sampling which is explained by Hesse-Biber and Leavey, (2011), as involving the identification of participants based on their accessibility to you (Leavy, 2017). However, snowball sampling ended up being the sampling method used in this research study. Snowball sampling is a process

whereby each participant leads to the selection of another participant (Alder & Clark, 2011; Palton, 2015). The first participant informed some individuals who were in our target group that would be interested in the study. Then we got responses from 2 individuals who helped us in getting subsequent participants. Snowball sampling is where earlier participants are asked to identify other potential participants that meet the study criteria. That is, the first participants led to the selection of other participants that followed in the recruitment process of the research study (Engwa Azeh, 2015; Leavy, 2017).

After, all the participants were informed about the purpose of the study, and a written consent form was sent to all participants for their approval before the commencement of the interview (see Appendix 2). Then, the interviews took place online via Google Meet and Zoom on different dates. The interview was 25 to 45 minutes depending on how in-depth the participants wanted to discuss their experience (see Table 1). However, all the required information was retrieved from the participants in accordance with the interview questions. Due to the Covid-19 pandemic and health protection recommendations, there were no contact meetings. The interviews were recorded with participants' consent and agreement for transcription and for further analysis. The interviews were conducted in English giving the interviewees and the interviewers comfort to describe their experiences and for understanding respectively.

There is no collective agreement on 'how many interviews should be conducted in qualitative research' (Dworkin 2012). The number of samples in qualitative research is expected to be less than that of quantitative research. Saunders et al. (2003) state that sample size depends on many factors, such as a study scope, quality of collected data, reliability of data, and so on. Due to the scope of the study, 5 interviews were believed to be adequate (see table 1).

Table 1. Summary of details of the interviews

Person	Place	Date of Interview	Duration
Participant A	Google meet	29.09. 2021	41 minutes
Participant B	Zoom	07.10.2021	34 minutes
Participant C	Zoom	18.10.2021	29 minutes
Participant D	Zoom	17.11.2021	43 minutes

Participant E	Zoom	22.11.2021	38 minutes

The table above summarizes the dates and times for the interview which was done online from September to November 2021.

## 5.2 Data Analysis

Data analysis usually consumes a lot of time for the reflection, and it takes from the beginning of the questions until the study is done. This study used a qualitative content analysis approach to analyze the data gathered from the interview. Roller and Lavrakas (2015, p. 232) defined content analysis as ‘the systematic reduction of content, analyzed with special attention to the context in which it was created, to identify themes and extract meaningful interpretations of data’ (Leavy, 2017 p. 146).

Content analysis can be applied in the understanding and analysis of meanings that are embedded within texts as well as through the context they were created (Leavy, 2017; Driska & Maschi, 2016). The use of content analysis in this study was to help us properly interpret the text which was documented after the interview with the participants. The content analysis looks at the themes and ideas through a process that involved data reduction, data grouping, and formation of the concepts that can be found in the participant’s response to answer the research question. (Kothari, 2004). The content analysis helped us determine the themes, and concepts that were found in the data from the interview as well as in the interpretation of the textual material (see Fig. 1).

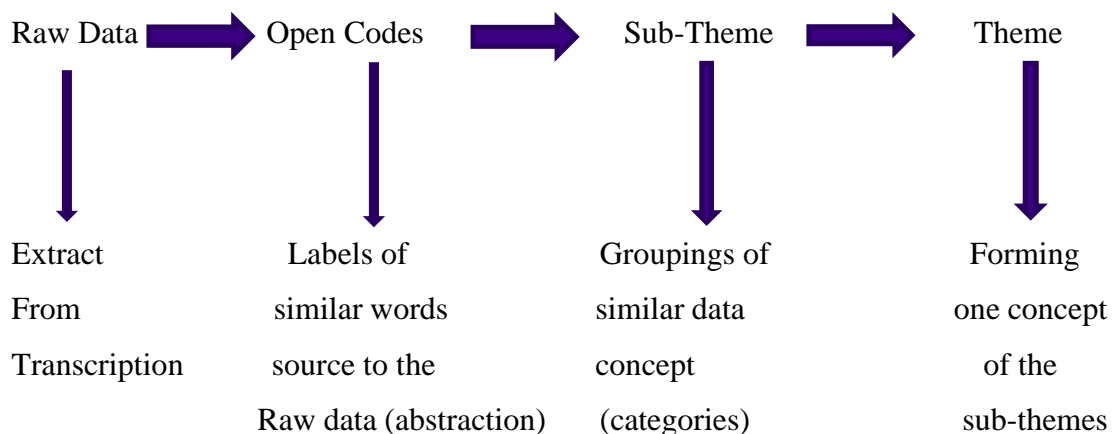


Fig. 1 Data Analysis Process of the Themes Derived (Driska & Maschi, 2016)

Firstly, the data analysis involved immersion of data through critical reflection for new ideas to develop and help enhance data reduction for accurate analysis (Driska & Maschi, 2016). In the process of the analysis, the researchers read, organized, and formed categories, or themes by comparing the similarities and differences between the codes (also referred to as labels).

Again, the analysis was based on the interview data generated from notes taken and recordings during the interview. Then the recordings were transcribed into textual data for reading and observing similarities and differences in the data. The textual data were read repeatedly to determine the coding assignment and interpretation. Similar ideas were obtained after being familiar with the data through the usage of Microsoft word tools.

Familiarity was achieved by reading the textual data several times (Leavy, 2017). The concepts were formed during the abstraction stage that is from the response of participants. Reduction of the data was done by coding suitable meanings that were relevant to answer the research questions by creating categories and abstraction from the data (see Appendix 1). After, the codes obtained were used to form sub-themes by comparing and contrasting similarities or differences between the codes thus grouping of codes, abstraction of the data for comparison to create sub-theme. At this point some of the abstraction ended whilst continuation of abstraction was done for the concepts that described the research phenomena (see Appendix 1). Then the sub-themes or sub-categories were grouped based on the similarities found in the codes to form the main themes. (Driska & Maschi, 2016; Kothari, 2004; Leavy, 2017).

## 6 RESEARCH ETHICS

Throughout the research study, we focused on trustworthiness and followed the ethical consideration of the university and that of the work-life partner. We also have an obligation as future social professionals to be accountable in our dealings with service users.

Leavy, (2007) describes ‘ethics as involving knowing what is right or wrong and acting on that knowledge’. Research must be based on morality, integrity, fairness, and truthfulness, ensuring that individuals are not in any harm because of the study (Leavy, 2017). The whole research process involved ethical considerations beginning with the topic, identifying our potential participants, the way we would interact with the participants, and how we would disseminate our study findings to interested parties (Kothari, 2004; Leavy, 2017).

Approval was sought from the Diaconia University of Applied Sciences represented by thesis supervisors, the work-life partner, and the participants before the study was carried out. The research questions, method, and data collection were reviewed with the work life partner, and the supervisors. In line with Diak guidelines, the thesis idea plan, research proposal, manuscript, and publication were presented for corrections, guidance, discussions, criticisms, and suggestion for the improvement of the thesis.

Potential participants were given invitation letters, followed by a consent form then the interview was conducted online, through Zoom, and Teams, since face-to-face interviews were not feasible due to the Covid-19 pandemic. We built trust and developed a rapport with participants by showing interest in their experiences and stories. The study was conducted in a non-judgemental manner, and we took into consideration the diversity of the participant’s views. For anonymity reasons the background of participants that was in the interview questions were not included in the findings of this study. Although this study used a snowball sampling method, participant cannot discover what others response were since the experience about their wellbeing is subjective and varying (Leavy, 2017).

Ellis, (2007, p. 4) defines relational ethics as recognizing values of mutual respect, and dignity between research and participants (Leavy, 2017, p.40). Therefore, ethical consideration was given to ensure biases of the data are limited or eliminated and unfair interpretation minimized as well. We ensured that participants' personal information was handled with care and were not disclosed. The limitation that occurred during our study was the collecting of the data and the time-consuming nature of the analysis. However, we ensured that it would not affect the interpretation of the data as there was a tendency to rush because we intended to comply with our thesis time schedule. (Leavy, 2017).

According to TENK 2019 updates, participants must sign a compliance or consent form for the research study. In this study, that compliance was adhered to whereby all the participants received an explanation for the study, and their consent was sought before the interview commenced (Finnish National Board of Research Integrity, 2019). The interview recordings and transcription were stored on a password-protected device. Accessibility to the study data was only visible to the students responsible for this research. The data gathered will be destroyed after the thesis publication (Leavy, 2017).

The study used appropriate academic books, journals, articles without biases or plagiarism. In accordance with anonymity, all the participant's identities were hidden. Again, the qualitative analysis of the data gathered, and the results were presented as it happened to ensure adherence to authenticity and reliability of the study. Expressions from the participant's responses were used in confirming the claim made in the results exactly as it happened. Further, the interview data recorded were transcribed verbatim to avoid pre-assumption. This was done through a systematic inductive analysis of the content of the interview data to ensure the credibility of the result by deriving codes from repeated readings (Kothari, 2004; Finnish National Board of Research Integrity, 2019; Leavy, 2017).

According to Engwa Azeh (2015 p.166) research validity is a 'conceptual and scientific soundness of the research study'. Thus, the result of the study is the true reflection of the data collected which was done in a non-bias manner. In adherence to the research ethics, no participant was forced or misled to participate in this study. The study did not provide any risk to the participant in any way.

## 7 RESULTS

This chapter presents findings from the data gathered for this study established on the research questions. The chapter dispenses the outcomes of the wellbeing of immigrant parents having a child with autism spectrum disorder in Finland. To arrive at the outcome of the study, three research questions were responded to:

1. What type of challenges do immigrant parents experience with having a child with ASD?
2. How do the experience of immigrant parents with children with ASD impact their lives?
3. What support does immigrant parents with children with ASD need in their everyday lives?

These main research questions were followed by sub-sections or segments for an in-depth (see Appendix 2). The qualitative content analysis revealed these themes from the participants data (see Appendix 1). This includes psychological issues, attachment, social relationship, cultural belief, knowledge acquisition, daily routine, and social support mechanism. The results are in line with previous studies which will be discussed in the next chapter.

### 7.1 Psychological Issues

The interview study revealed that some participants did not accept the diagnosis, whilst some also did not understand the whole situation. In line with previous studies (Pozo & Sarria, 2015; Arfa et al., 2020; Giallo et al., 2011), some parents find it difficult to adjust to the diagnosis of their child. Some participants responded to their children's ASD diagnoses as:

*I was shocked and could not believe it even till now, I still do not accept the diagnoses. (P2)*

*I was confused and did not understand in the beginning due to my cultural belief as it was believed that it was punishment from the gods. (P3)*



*For me it was a very sad moment to know that my child has a condition that no medication can cure but managed with only therapies. (P4)*

*We were disappointed and refused to accept the diagnosis. ( P5)*

The participants had divergent views about the diagnosis. Although majority of the participants were saddened with the news, one participant anticipated it and thus was not surprised with the diagnosis. Having a prior knowledge of the child's situation decreases the shock and disappointment because of the diagnosis on the parents.

*It was something I knew already as I noticed when the child was a year plus old. I noticed some unfamiliarity and I asked Neuvola (child health clinic, parental clinic) for the diagnosis. However, it was done when the child was 3 years old. (P1)*

Most of the participants felt that there is some form of stress in taking care of a child with ASD, emphasising that parenting itself is a difficult job and involves some level of stress which is inevitable. Therefore, it will be good for professionals to educate the parents more before or after the diagnosis.

*I had to travel back home for family support for almost a year when my child was 3 years old as my partner and I were stressed with the whole situation. (P3)*

The results correlate with previous studies (Arfa et al.,2020: Lehti et al., 2018: Giallo et al., 2011), that states that caring for a child with ASD can be stressful for some parents whiles other parents experience anxiety, and depression compounded with navigating in a new or foreign community. The studies further indicated that degrees of stress, and anxiety were in lower levels of ASD adolescent than in younger children with ASD. That is, as the children grow, they try to be independent and doing things on their own with minimal or no supervision. Stress, disappointment, and loss of hope were identified in the study to have impacts on the wellbeing of the parents. Stress includes thinking about the situation and the child and trying to keep a balance in doing daily activity. Disappointment was seen involving the diagnosis of the child and how they feel hopeless about the situation.

For instance, P4 lamented:

*Most times thinking about my child's future and if ever my child will be able to cope with day-to-day life independently. That has been my concern every day.*

According to the participants, there are lot of challenges involved in parenting or taking care of a child with ASD which includes being vigilant and always exercising carefulness. A response from P1 was that:

*My child is overactive and extra care must be taken when left alone. I recall my child once run off from the house when she had been dressed, running out to the cold nude and causing fear and panic to us.*

## 7.2 Attachment

The parent-child attachment was represented in the interviews as the bond parent had with their child. The times they share together and engage in activities daily. All participants agreed that they spend lot of time with their child thus the child loves to be around them most times. Below is an exemplary quote of participants:

*My child wants to always be around me. My child is overactive and extra care must be taken when left alone. The time we spend together each day makes our bond stronger. (P1)*

The results indicated that parents become more closer to the child to monitor any hyperactive behaviour. The close relationship enhances the bond between parent and child because of spending time together and doing things together such a playing games and reading together.

*My child is always happy, jumping around, and wants to be carried most of the time despite the age now. (P3)*

As the child grows the dependency on the parent declines as the child tries to be independent. The child learns from the daily routine and can comprehend what every day must be like.

*My child used to be closed to me often but now likes to play alone. (P2)*

However, it can also be noticed that as the child grows, the dependency on the parent or guardian decreases. Children learn to do things independently as they grow particularly when there is familiarity in their daily activities.

### 7.3 Social Relationship

Another issue facing immigrant parents with children with ASD is social relationships. Some of the participants agreed that they find themselves isolated due to their child's condition. This can be attributed to the ignorance of people on ASD and thus tend to ask many questions such as why is your child behaving that way.

*Sometimes I do not want to attend parties or other occasions because I feel my child will draw unnecessary attention to us. (P3)*

*Not being able to go to some places because it might not be conducive for the child, missing out on functions, and not even being able to leave my child with friends because they might not understand my child when in a meltdown mood. (P4)*

One response from a participant further relates their social relationship to stigma. All the participants agreed that they find it difficult to go into the midst of people due to the prejudice and behaviours of people towards them and their children.

*It affects my confidence level, I fear taking my child to crowded areas with people staring at us, avoiding us or saying things about my child. (P2)*

The uncertainty of not knowing what will happen outside of their comfort zone that is their home, makes it difficult to create social ties with other people. Forming relationship with people seems a difficult thing to do as participants want individuals that are non-judgemental to be around them.

#### 7.4 Cultural Belief

Most of the participants had their own cultural beliefs about ASD and how it affected their understanding and perception of the situation. Most of the perception are negative and does not encourage one to embrace the situation.

*We rejected the diagnosis because we did not know how the community will see us based on where we come from. They believe such a child is not worthy of being in society and thus is a fetish child. (P5)*

Some cultures have beliefs that a child with ASD is inhabited by a spirit thus being referred to in the above response as a fetish child. Some cultural beliefs influences our thinking and can also provide positive reliefs for the people who believe. This can be seen in the response of P2:

*I just have to believe and hope for a miracle to happen for my child to talk as that is the only problem, I can see my child has.*

Another participant's response shows a believe in God and how things will be in having such faith. Thus, the faith brings a sort of comfort for the person to ease the situation or the challenge the person might be facing.

*I believe that God will not give you something that you cannot handle or manage. I believe it is my fate and I must accept it. (P1)*

Cultural belief was a source of inspiration that helped some participants manage their life challenges and found ways of resilience to deal with their situation. Individuals from the same cultural backgrounds can also have different attitudes or behaviours towards life experiences that can influences their perceptions of things.

#### 7.5 Knowledge Acquisition

All participants agreed that since the diagnosis of their children with ASD, they keep researching the topic to understand the condition well and enable them to relate well with their child. Learning has no end therefore continuous or periodic monitoring of the child situation must be done not only by professionals in the field but also by the parents who spend most time with the child and to observe any familiarity or new behaviours in the child.

*We do lot of information search about our child's condition because I understand even the professionals who are working with us do not know everything. It is therefore important to study my child's development and observe what helps improves or worsens the condition. (P3)*

Learning about the condition helps the parents to observe and monitor their children's development and it influence the choice of activities and food. Some respondents found from their research on ASD that reducing the child's sugar intake decreases the hyperactive behaviour. A response from P5

*We use many tricks in activity or playing. When it comes to food, we do not usually give sugary things because of the excess energy it gives to the child. Then when it comes to mobility like running, we change the run to games, run to pick the ball, and run back again to pick another one. In irritation as a child with autism, eating with bare hands irritates my child, yet we encourage the use of eating with hands and is helping.*

*I do a lot of research on my own to help understand the situation. I found out that reducing my child's sugar intake will reduce the child's hyperactive behaviour. I also noticed that when my child stops taking milk, she starts sleeping well. So instead of milk, I gave my child an almond drink. (P1)*

Most participants become more knowledgeable after the diagnosis of their child with ASD. Continuous learning and monitoring of the child's situation is vital for the development of the child. For example, knowing the things that can cause any disturbance in the child's behaviour and attitude helps in eliminating the chances of irritability or any hyperactive behaviour.

## 7.6 Daily Routine

With regards to having a daily routine, all the participants concur that it is vital for the child's development and for limiting misunderstanding. When children with ASD have a regular activity daily, it enables them to function well daily as they understand and know what to expect at each time of the day.

*We do every day reading books, playing with Legos, building trains, hide and seek, tickling, singing nursery rhymes, going to the playground, and taking a walk and also cooking together if the child is interested. What has helped is having a routine and explaining beforehand what is going to be done and if there's going to be a change in routine. (P4)*

Although the daily routine helps the parents to be organized, it can sometimes be stressful when the parent fails to fulfil some of the activities. One participant lamented:

*Sometimes I feel stressed because am unable to handle the daily routine. (P3)*

Being conversant with a daily routine or activity enables the child in becoming independent. For instance, when the child knows that after coming home from playing at the park, the child must first wash the hands helps the child in doing that activity by themselves without being told to do so. Even though some participants complained about been stressed due to their inability to keep up with the child's daily routine, it is a factor that helps the child to adapt to situations and changes that might seem confusing for the child.

### 7.7 Social Support Mechanism

Most of the participant also agreed that they receive professional and financial support from the municipality and the health sector. Managing of ASD is done effectively with periodic assessment and therapies which can cause financial burden to the parents or family. However, in Finland, there is social support given to families to minimize the financial burden on the family.

*We get a lot of support from the health and social service. (P2)*

*They have been of great help by following up with yearly appointments to evaluate my child's situation and recommend the necessary help needed. (P4)*

*I get informal care from the municipal. I have two days' holiday from taking care of my child. I get a disability allowance from Kela and the municipal for my child's upkeep. (P1)*

*We are grateful Finland really offers a lot of help. We got help from Kela and lastenhoitaja HUS refers us to a lot of connections that gave us the help we needed. (P5)*

Having a child with ASD involves a lot of hospital visits and check-ups which can be financially draining when one is unable to keep up with the financial demands of the situations. It is therefore, a good relief that municipalities and government policies help to provide services and professional hands to citizens or residents in Finland. This is a relief because parents are not burden with such financial duties. This form of relief can help improve the wellbeing of the parents.

The results indicated that most of the participants though did not expect the ASD diagnosis of the child, have been able to manage their challenges by having daily routines, searching information, and receiving support from social and health sector.

## 8 DISCUSSION

This chapter discusses the outcome of the interviews conducted on the wellbeing of immigrant parents with children with ASD. The research aim was to highlight the challenges immigrant parents face in everyday life of taking care of their children with ASD and how it affects their wellbeing. The research questions used to obtain the solution to the research goal were: ‘What type of challenges do immigrant parents experience with having a child with ASD?’ and ‘How do the experiences of immigrant parents with children with ASD impact their lives?’ ‘What support does immigrant parents with children with ASD need in their everyday lives?’. The results of the study are psychological issues, attachment, social relationship, cultural belief, knowledge acquisition, daily routine, and social support mechanism which are discussed in relation with other previous studies (Pozo & Sarria, 2015; Arfa et al., 2020; Giallo et al., 2011).

The study identified several responses and mechanism used by immigrant parent to cope with having a child with ASD in Finland. The results indicate that the study participants experience a series of challenges in taking care of their children that affects their wellbeing positively and negatively. The results identified in this study are in line with previous studies in relation (Arfa et al., 2020).

This study shows that psychological issues were one major challenge immigrant parents with children with ASD face. Stress is a tricky thing to define and diagnose, and professional and layperson opinions of stress might differ considerably. Stress is understood as a negative emotional and tension-inducing state arising from a situation that is experienced and too demanding to cope with. In Finland, the diagnosis of ASD may involve a long process which can sometimes put stings on the person and their loved ones, and this can cause stress to the parents (Autism, Finland). Attending several appointments in a bid to ascertain the child’s diagnosis can induce tension for the parents. This tension and the unknown can influence an individual’s emotions negatively. Thus, the wellbeing of an individual is affected by their stressful situation (Marshall & Long, 2010). All the participants mentioned stress. We observed that some were not stressed because they have children with ASD in the family, the stress is due to confusion on what to do, how to manage the daily routine, and how to cope



with the current situation. However, some were able to manage and overcome their stress although at the beginning of the diagnoses it was not easy but as time went by, they started to adapt to the situation, and were able to plan a better way forward. Several studies in autism (Gray, 1992; Wolf & Noh, 1989) suggest that parents with children with autism experience depression or dysphoria. Again, some studies suggest that parenting falls more heavily on the mothers than fathers. However, both parents experience parenting stress in various ways which can affect their wellbeing. (Marshall & Long, 2010.) According to Weiss et al., (2014), emotional and psychological wellbeing might be experienced by parents with children with ASD. This is due to the imbalance in managing the responsibility as a parent as well as the wellbeing of the family. The challenges can cause fatigue and stress for the parents which are reflected in the responses of the participants of this study (Arfa et al., 2020).

According to Yirmiya et al., (2012), attachment refers to the emotional closeness children create with their caregivers or parents that elicits feelings of security. The attachment involves close relationship that is, spending time together. Children with ASD form attachment with their parents the same ways as typically developing children. Participants realized that their children found sources of comfort from warm interaction with them. The parent-child attachment can be an influencing factor in the development of the child. This study indicated that parents form emotional closeness with their children daily which makes the children feel safe. The secured attachment used by most participants enhanced both parent-child wellbeing as the child feels safe in their environment whilst the parent was able to relate and understand the child's behavioural patterns (Rhodes, 2015). Secure attachment is a protective factor whereas insecure attachment is a risk factor whether the child without ASD or a child with ASD. The field of research on attachment noted that there were few studies on attachment and ASD due to the previous assumption that children with ASD do not form an attachment with their parents. In contrast, parents formed a secure attachment with their children through spending time and doing daily activities (Yirmiya et al., 2012).

Some participants had inner anger relating to their child's condition and are unable to build a strong system of self-help. This anger may affect their personal and social wellbeing. However, some of the participants were able to activate their resilient ability which helped them cope with the situation (Rhodes, 2015). Understanding

different cultures enhance our communication and working with others from diverse background thereby limiting the incidence of conflicts in interaction. Some of the immigrant parents' expressed anger because the professionals working with the children do not acknowledge their culture which sometimes generates helplessness and loneliness for the former (Rhodes, 2015). All the participants come from different cultural backgrounds with their own perception or understanding of ASD. Some of the participants' responses indicated a belief in God concerning their children's condition. According to Ponde and Rousseau (2013), child-raising practices can be influenced by cultural beliefs and practices that differ within any immigrant community. The research further noted that perception of ASD is also influenced by parents' cultural beliefs. Responses from some participants showed that it was God's will for them to have children with ASD which is affirmed in previous studies. Grinker et al., (2015) study on cultural adaption noted that ASD can be seen by cultural or spiritual believers as God's will or punishment. This belief helped the participants to adjust to their situation (Kang-Yi et al., 2018).

Parker et al., (2011) described spirituality as a more personalized act that provides support for families with children's disabilities in areas of patience, strength, and coping in daily life. Some of the participants' spiritual beliefs shapes their attitudes regarding how they see challenges and cope with them. Their religious practices provide some sort of empowerment to them. Some of the participants found solace in their cultural and spiritual beliefs that helped them to cope with the situation. Parker et al., (2011) noted that several studies on religiosity involving parents raising a child with a disability indicate that religiosity can be a resource for parents in terms of adaptation and resilience (King et al., 2006; McCubbin & McCubbin, 1993; Roger-Dulan, 1998; Skinner et al., 2001; Marshall et al., 2003). Parker et al., (2011) stressed the need for professionals working in the field to be aware of the importance of religiosity in families that practice it. According to Speraw (2006), the failure of some professionals to recognize the importance of religiosity in families that practice such faith had a hurtful experience to the parent raising the child with a disability which had been indicated in previous research as well as in this study (Parker et al., 2011). During the interviews, some participants said their religious beliefs are so vital in the way they accept and raise their children. Some said that rejecting unwelcome news is an act of faith, that draws them closer to God and eases their stress by increasing their resilience to challenging situations.

ASD is a lifelong condition and the approach used to manage the stress is vital for the wellbeing of both the child and the parent (Kang-Yi et al., 2018; Arfa et al., 2020).

Social relationship of participants was identified in their response of inclusion and exclusion in the interview. The results of the study revealed that most of the participants isolate themselves from society due to prejudice and attitudes of some people regarding them and their children. Social exclusion is a process in which one is excluded or is becoming excluded from participating in the world one lives in, in terms of cultural activities. Most of the participants had communities that organizes parties or social gatherings. However, they are sometimes unable to attend such gatherings (Burchardt et al., 2002; United Nations 2016). Consequently, this exclusion significantly influences their living standard and how they perceive society's fairness and unity. (Levitas et al., 2007). Some of the participants shared with us how they felt socially excluded from normal activities in society, due to the hyper-activeness of their children. Therefore, they prefer to create indoor games for themselves and their child rather than take them out to meet other people. This can diminish the confidence level of the parents thereby affecting their wellbeing negatively (Rhodes, 2015).

Most of the participants found ways to learn about ASD and the kind of resilience that allows them to act in a positive manner when facing adversity. Again, some of the participants have been able to identify the risk and protection factors in a bid to ensure the child is always safe and in a happy mood (Rhodes, 2015). Immigrant parents are less likely to contact professionals about their concerns, although everyone receives a similar type of care in Finland. Therefore, some of the participants sought to search for information about their children's situation by researching the topic (Heino & Lillrank, 2020). Building strong relationships with professionals was identified as one of the challenges that participants face as some professionals are not culturally sensitive to the diverse needs of the immigrant parent, thus, compelling the parents to research for information themselves (Arfa et al., 2020).

Predictability of things and events is vital in ASD people. Changes in their routine may cause anxiety. Performing a repetitive task can increase the ASD person's inclusion in the family or society which asserts the participant's response on having a daily routine (Autism Finland). All participants responses revealed that children learn best from repetition, children with ASD enjoy predictability, patterns, and having daily routines

at home can promote positive bonds between children and the parents. Performing daily routines can be comparatively difficult for children with ASD. However, having a step-by-step activity for the day can help the child to focus and function well. When daily activity becomes familiar to the child, it enables the child to recognize each activity and follow it. This form of daily activity repeatedly helps the participants in reducing stress due to confronting inappropriate behaviours from the child, thereby enhancing the wellbeing of the parents positively through the daily routine. (Arfa et al., 2020; Giallo et al., 2011; Rhodes, 2015.)

Finland's financial support for families is among the best in the world and one is entitled to them if they are covered by the Finnish Social Security or have a municipality of residence in Finland (InfoFinland). The participants in this study highlighted the continuous support they receive from social and professionals working in the field, and it makes them feel a sense of belonging in the society. Some support services are optional to use, and some participants perceive that the support was not needed because it does not help them in any way. The stresses of ongoing financial expenses associated with the cost of treatment can affect the wellbeing of the parent. The financing burden was one challenge that immigrant parents face in other previous studies (Arfa et al., 2020; Giallo et al., 2011; Green et al., 2020). However, one of the most surprising results of this study was that the parents did not face such financial burden and attributes it to the municipalities in Finland and the government who through their care, support and policies provide services that enhance the life of the person with ASD and their families. Most of the participants spend lot of time with their children, therefore, are not able to take up demanding jobs. Thus, if the participants were faced with financial burdens, their stress levels will impact their wellbeing negatively (Autism, Finland).

As noted by Heino & Lillrank, (2020), most parents want their views to be taken into consideration regarding their children's treatment. Therefore, inappropriate health and social service have an impact on the immigrant parent's everyday life which include stress which can hamper their integration process into the country. Also, lack of shared language, cultural diversity, and unfamiliarity with the service can have a negative impact on their wellbeing. (Heino & Lillrank, 2020).

## 9 CONCLUSIONS

This chapter focuses on how the research questions have addressed the purpose of this study. The chapter provides a summary of the study with its key findings, professional development related to the study, and recommendations made for further studies in this field.

### 9.1 Summary of the Study

The study explored the wellbeing of 5 immigrant parents with children with ASD in Finland. The study was conducted using the qualitative research method approach to analyse the participant's responses to interview questions. The research's aim was to highlight the challenges immigrant parents face in everyday life of taking care of their children with ASD and how it can influence their wellbeing.

Overall, the qualitative research has been fruitful and productive. The main idea was to gather evidence and views from our qualitative research done on the participants. Through the interviews, listening, and learning from their various daily challenges, we appreciated the subjectivity of each journey relating to their lived experiences. Although most of them had similar experiences and challenges, there were some who perceived their challenges as normal challenges of taking care of a child.

This research also highlighted difficulties of parenting a child with ASD and getting appropriate knowledge that will be in the best interest of the child as well as to the parent. Most parents complained that they were stressed, confused, sad, and had difficulties coping with the situation, especially during the beginning of the diagnosis, which affects their wellbeing in one way or the other. Some needed more help from the community to help them adjust to their situation. Thus, they would have liked to see more materials or platforms for immigrant parents with children with ASD. For example, some parents did complain about their children exaggerating activity, and how it influenced their involvement in a social gathering.

In addition, stress was discovered in this study as a significant challenge experienced by immigrant parents with children with ASD. Again, the study revealed that the

parents had strong relationship with the child and perceived it as the most valuable in their lives irrespective of their condition.

Wellbeing of the parent is necessary and valuable, as it has a significant influence on the child as well. A happy and healthy-minded parent can impact a positive functional ability for the child. Some experienced challenges in balancing their wellbeing or not even considering monitoring their wellbeing, thus forgetting that unhealthy parents cannot be able to assist their children. The study shows that immigrant parents with children with ASD have challenges that influence their wellbeing positively or negatively daily.

Furthermore, the results revealed that immigrant parents had limited knowledge about ASD at the beginning of the diagnosis. It is therefore essential for professionals working with these parents to support them to understand the situation. This finding suggests that raising professional knowledge should alleviate challenges and improve the wellbeing of the parent with a child with ASD.

The limitation of this finding was the sample size which was relatively small compared to the pool of immigrant parents living in Finland. Therefore, a larger sample size would allow conduct in-depth comparisons across the country. Again, the study was conducted in English thereby preventing other potential participants who could not speak English but were willing to participate. Despite these limitations, this study identified vulnerable immigrant parents who are experiencing challenges that affect their wellbeing positively and negatively daily.

## 9.2 Professional Development

There has been a tremendous development to our professional growth. We have acquired more knowledge and skill competencies at different levels of this thesis journey. This study challenged our ability in research such as generating research topics, ideas, aims for research, the study method, analysis, and ethics related to implementing a research-based study.

Juliana: With my background as an immigrant, this study challenged me in having an open mind without prejudice during the study process. The ability to respect different opinions, manage deadlines set for accomplishing tasks, and have healthy conversations throughout the entire process was challenged. However, I managed to conquer the challenges encountered.

Again, understanding ASD has increased the knowledge of this social service profession. Furthermore, this study process has enhanced my confidence level to overcome the nervousness experienced during presentations. Interactions with participants, thesis supervisor's advice and comments, working life partner's comments were motivations for the progress of this thesis.

Professional development in self-control increased in this study especially listening to the tearing stories of some participants during the interview. My skills of listening and interviewing have also improved drastically which I will use as a social service professional in future research and projects.

Jennifer: The journey helped me to improve in my professional growth in various areas, gaining more deeper knowledge, understanding, skills, doing more research, ideas, topics, study methods, analyzing, and having tools for a research-based study.

Beginning the journey seemed easy but was in no way easy, many efforts had to be added to make the journey smooth. Coming from an immigrant background was easy to help us flow, understanding each other's point of view, knowing that each suggestion is welcomed amicably, having mutual agreement, understanding, motivating, and supporting each other. Knowing that we are working on common goal which is to make our thesis a successful one without any complications. Perfect that we victoriously manage to handle all this peacefully without any issues.

Understanding ASD is interpreted differently by different people, and it has many types, minor and non-minor. It opened my eyes to learn about different signs of ASD, and to know every child is different. It enlightened me for my future in the case of my study field as a future social service worker. Interviewing the participants increase my boldness, receiving comments from the supervisors and students during presentations, and interaction with our work-life partner, was my motivation in working towards our target goal which is the success of the study.

This was a training process for me in the professional aspect. How to use empathy instead of sympathy, confidence, ability to put more effort, accepting corrections, and learning from other colleagues, increased my listening skills.

### 9.3 Recommendations

There are lots of research studies and articles about ASD. However, there were a few of that studies that corresponded to the aim of this study. Therefore, it is appropriate to do further research into this study to produce the best results. Also, have a supportive mechanism for immigrant parents with children with ASD to enhance their ability to cope with the everyday life of taking care of their child which has a significant influence on their wellbeing.

There is information about ASD, the process involved in diagnosis and treatment. However, there was little information on the website of the association of autism in Finland about coping mechanisms that could be used by parents to enhance their wellbeing (Autism Finland). Our findings will help social service professionals and other actors involved with immigrant parents with children with ASD.

According to the study findings, there is a need for more platforms like social media groups specialized for ASD family and child welfare social workers, and other actors interested in this field. This will ensure that the less-experienced parents would be able to learn faster on how to manage their lives as well as make the life of the child better. From our participant's answers, no one mentioned special social gatherings for such children and their parents, we recommend that actors, professionals, or municipalities should create such options, in that case, parents can communicate with others, share ideas, and have a sense of belonging. Due to covid-19 restrictions, contact meetings may not be allowed however, they can be done online.

We recommend organizing events, webinars, or seminars through which parents can learn and understand ideas on how to mould the child mentally, socially, and intellectually. This will reduce the stress and enhance their wellbeing.



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## APPENDIX 1. Themes derived from the data analysis

Extract of Expression (Only few for anonymous reasons)	Initial code Comparing and contrasting	Sub-theme	Theme
<p>I feel devastated but what can I do.</p> <p>It was stressful when my child was younger.</p> <p>I was shocked and could not believe it.</p> <p>Am stressed and still do not understand the situation.</p> <p>The situation affects me in many ways such as my confidents level.</p> <p>My biggest challenge is not knowing how best to help my child.</p>	<p>Helplessness</p> <p>Stress</p> <p>Distress</p> <p>Fear</p> <p>Shock</p> <p>Uncertainty</p> <p>Confused</p> <p>Disappointment</p> <p>Doubtful</p> <p>Misunderstanding</p> <p>Hopelessness</p>	<p>Despair</p> <p>Stress</p> <p>Depression</p>	<p>Psychological issues</p>
<p>My partner believes it is connected to spirituality.</p> <p>I believe that God will not give you something that you cannot handle or manage.</p> <p>I just have to believe and hope for a miracle.</p>	<p>Spirituality</p> <p>Believe</p> <p>Assumptions</p> <p>Hope</p>	<p>Believe</p> <p>Spirituality</p>	<p>Cultural Belief</p>
<p>We get a lot of support from the health and social service</p> <p>My partner support me a lot in caring for the child.</p> <p>I get informal care from the municipal.</p>	<p>Professional Assistance</p> <p>Monetary assistance</p> <p>Social care</p> <p>Family support/care</p>	<p>Social Support</p> <p>Social care</p>	<p>Social Support mechanism</p>

## APPENDIX 2. Consent Form

Dear participant,

We are students at the Diaconia University of Applied Sciences, pursuing a bachelor's degree programme in social services. We are writing our bachelor's thesis in collaboration with Familia Ry and the topic is 'The Wellbeing of Immigrant Parents with Children with Autism Spectrum Disorder'. The aim of this study is to highlight the challenges immigrant parents face in everyday life of taking care of their child with Autism Spectrum Disorder (ASD) and how it affects their wellbeing. It focuses on your experiences, how you feel about your role as a parent, how you feel about your wellbeing, and how you deal with challenging situations if any. In this interview, all responses will be confidential, and the data will be judiciously disguised to protect your real identity. The interview will be audiotaped (recordings will be destroyed after the thesis publication) if you want us to do so otherwise the interview will be done according to the participant's wishes. However, you have every right and freedom to opt-out or participate as participation is voluntarily. All participants will be offered the opportunity to read and comment on the draft of their opinions shared if you want before it is published.

Thank you.

DATE: .....

STUDENTS: Juliana Amoakoah Abrefa, Jennifer Chinenye Okonkwo

THESIS SUPERVISORS: 1. Hanna Lamberg  
2. Marianne Nylund

PARTICIPANT'S SIGNATURE: .....

## Appendix 3.

### Interview Questions

#### Background

Before we begin, could you please fill/tick/tell the appropriate group?

1. How long have you been living in Finland?
2. How old is your child?
3. Age group below 20....20-29.....30-39....40 and above.
4. Are you in any or aware of any organization that support immigrant parents with ASD children?
5. Have you participated in any of Familial projects?

What type of challenges do immigrant parents experience with having a child with ASD?

- Could you please share with us what kind of experience you had after been told about the diagnosis of your child with ASD?
- Could you please describe how you spend time with your child?
- How do you feel as a parent having a child with ASD?

How do the experience of immigrant parents with children with ASD impact their lives?

- How does the condition of your child affect your daily life?
- What has been your biggest challenge times in taking care of your child?
- How do you feel about your general wellbeing?

What support does immigrant parents with children with ASD need in their everyday lives?

- We would like to know how you deal with or cope with having a child with ASD?
- How does the health and social care support you?
- What support do you think you need but do not have access to?
- What would be your advice for immigrant parents whose child has just been diagnosed with ASD?