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Communication methods between home and school with adolescents  
between the age of 17 and 20 with Autism Spectrum Disorder (ASD).

A Comparative Study of the Narratives of Families in Finland and the U.S.

Master's Thesis

Vaasa 2018



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## UNIVERSITY OF VAASA

**Faculty of Philosophy**

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<b>Masters' Thesis:</b>	Communication methods between home and school with adolescents between the age of 17 and 20 with Autism Spectrum Disorder (ASD)
<b>Degree:</b>	Master of Arts
<b>Date:</b>	2018
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**ABSTRACT:**

This qualitative study identifies and examines the experiences of parents with adolescents between the age of 17 and 20 with Autism Spectrum Disorder (ASD) on the communication methods between home and school in Finland and in the U.S.

The aim was to find out how parents maintain involvement in their child's education and what kind of obstacles the parents face in communication. The study used the narrative analysis method and data was collected through participating parent's observations and via storytelling by parents with children with ASD. The interviewees of this study were two Finnish parents with their children with ASD and two American parents with two adolescents with ASD. These interviewees were recruited through the member associations of the Finnish Association for Autism and Asperger's syndrome in Finland and the Modesto School District located in California, U.S. The data was collected in the U.S. during summer 2014 and in Finland during spring 2015 and analyzed in the fall 2015.

The results concluded that the parents of children with autism in Finland felt that they needed better communication methods, such as face to face meetings or discussions in phone with school personnel. That will support the parents raising their child with autism. The parents living in the U.S. were experiencing lack of support by the professionals when identifying the needs of the child with autism in school. The results showed that communication between home and school in the U.S. was more consistent than in Finland. Only in the U.S. the participants felt that a valuable way of establishing good relationships between parents and teachers was spending time together on the school field trips.

In both countries the parents experienced difficulties at school: impolite attitude and behavior of the professionals and for most importantly the lack of communication as issues which increased the workload and stress of the families with the children with ASD. The research data can be used to designing of communication pathways within special education at schools, concerning the parents with adolescents with ASD, to make their needs to be met more appropriately.

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**KEYWORDS:** autism, parental involvement, communication method

## 1 INTRODUCTION

There's an ancient African proverb "It takes a village to raise a child" that I know is true especially when it comes to Autistic children with all ages. Today this village is not just so much a group of neighbors, but it represents a whole community of professionals: teachers, aids, therapists, doctors, consultants and other workers who all support the family and help the Autistic child to be successful. The child's needs become the focus for many adults and knowing from my own subjective experiences as a parent of a child with autism, communication becomes a crucial component. Especially when the school starts for children with Autism Spectrum Disorder (ASD).

In Finland the topic of communication between home and school as a theme for research – in Finnish environments - is quite limited. This relative lack of studies can be perceived for example from EBSCO-, ERIC-, HELKA- and Fennica- databases. There are of course several master's theses on the topic, but only few dissertations, articles or other high-level studies.

It is good to remember that according to a major international student assessment program, PISA (Programme for International Student Assessment), conducted by Organization for Economic Co-operation and Development (OECD), students in Finland are one of the best academic performers among the European countries. Finland has ranked very high in PISA survey since 2000 (Sahlberg 2007). A good question to policy makers might then to be asked, whether this has something to do with school-parent relationships.

### 1.1 Background

Over the past two decades many longitudinal studies have been conducted in the United States about parental involvement in both general education and special education field (see, for example, Walker, Colvin & Ramsey 1995; Darch, Miao & Shippen 2004).

Walker et al. (1995) indicates that parents' involvement within general education in schools increase student academic achievement. The improvement overall includes better test scores, better grades, increased attendance, higher homework accountability and positive student motivation and attitudes about schoolwork among the students (Darch, Miao & Shippen 2004: 25).

Spann, Kohler & Soenksen (2003) examine the home-school relationships and the ways that communication impact these relationships. One of the most common reasons for having communication between families and school personnel is to exchange information related to the child's needs and performance at school. Another important goal for home-school collaboration is to teach children self-advocacy. The most effective home-school communication occurs on a regular basis and involves the child's teacher or paraprofessional. The most typical situation involves brainstorming to solve problems that come up either at home or at school. Several parents indicate that teachers called them when children experienced difficulties. On the other hand, parents feel that they did most of the work to maintain correspondence with school. However, despite similar concerns, parents express high to moderate satisfaction with the communication that they had with the school their child attended.

Previous research has also focused on the importance and effects of parental involvement and participation in educational settings involving students with disabilities. Studies by Koegel, Koegel & Schreibman (1991); Bailey & Wolery (1989); Stancin, Reuter, Dunn & Bickett (1984), Newmann & Wehlage (1995) and Epstein, Salinas & Jackson (1995) show positive impact of parental involvement with special education students, when there is an open communication and interaction between parents, teachers and peers.

Davern (2001) focuses on what can be done to build productive partnerships or strengthen existing relationships between parents and teachers of general education classes. The research consists of 21 participants. Parents praise some professionals as very skillful in reducing the psychological distance between staff and parents. The analysis of the interviews shows that connecting with parents as individuals is the key to a meaningful home-school communication. Parents' perspective concludes that some of the teachers

were able to create an atmosphere where parents did not feel that they had to watch their behavior. Staff practice these methods by their choice of interaction styles. Teachers' interest in parents' ideas felt authentic to parents.

Davern's (2001) study also points out that it is important for teachers to consistently communicate to parents that they are enthusiastic and welcome children with special needs in their class. Several parents value teacher's ability to understand how very important it is for parents to hear that the educators believe in their children and truly want to see their potential. It gives parents strength when they feel they receive support from the school professionals. Teachers should also let parents know they hold as high expectations for their special need children as they do for their typically developed peers in classroom. The parents express their appreciation to the teachers who attempt to put themselves in the shoes of the parents to see what it truly means to have a child with autism.

On the other hand, some parents felt that staff had vague beliefs about them and their abilities as parents of a child with special needs. It was observed that educators demonstrated lack of knowledge of their student's disability. The problem arises when people start to apply different stereotypes. Davern suggested that teachers would need more opportunities to practice combatting the impulse. The staff would need encouragement and support to challenge stereotypes and see individuals instead. (Davern 2001).

Moreover, parents feel that building relationships take commitment involving both sides and require team work. Parents' recommendations conclude allowing more flexibility from school staff in setting up meeting dates and times that will help tremendously to attend IEP (Individual Education Plan) meetings. (Davern 2001).

Federal Law in the U.S requires the educators to invite parents with children with special needs into the planning process called IEP (Quinn, Gable, Rutherford, Howell & Hoffman 1998: 1). But still not always does this collaborative outcome materialize in the way how the legislation has envisioned it. Quinn et al. (1998) notes that several parents point out

that educators give up too soon or are quick to release parents, who don't attend IEP meetings.

Bouakaz (2007) studied parental involvement in an urban school in Sweden. This case study focuses on what promotes and what hinders parental involvement in an urban school for students between the age of 12 and 16. The two methods used in this study were critical ethnography and participatory action research. The data is collected by interviews with both the teachers and the parents as well as with observation within the school. The results were that school and home should be working together. Collaborative approach does impact positively the communication between home and school and eventually leads to student success. Teachers view parental involvement so that parents should be engaging themselves more in the child's schooling. Parents feel their involvement is to motivate and encourage the child in their studying. On the other hand, parents are more interested in a shared responsibility by establishing a parent-teacher association (PTA) or getting together arranging different activities for their children. There is a need for the better communication methods for parents. The schools see it necessary for the parents to support their children and for them to have a genuine interest of how their children are doing. The teachers believe the parents are being interactive, helpful and supportive towards them, although they do not expect the parents to be willing to initiate things at school. (Bouakaz 2007: 157, 270).

Bouakaz's (2007) discoveries seem to differ from Lehtolainen's (2008) study as teachers and parents had different understandings of home-school collaboration. Instead, Bouakaz's (2007) study shows quite similar findings to the studies made in the U.S by Davern (2001). Davern's study clarifies that connecting with parents as individuals is the key to an important home-school communication.

Tonttila's (2006) longitudinal study shows how the whole family can be helped to cope better by supporting the mother with an ASD child. The study also indicates that professionals at school are capable of supporting parents. The point of the study is the subjective experience of mothers and the dialogue between professionals at school and the mothers.

The research data was collected by interviewing 10 mothers who have a child with a disability or autism, 8 staff members in the day care and 6 teachers at school. Altogether there were 32 interviews and 24 informants. The mothers were interviewed first in 1998 and then after five years in 2003, with the purpose of getting information on whether mothers' life situation had changed and if so, about the nature of those changes.

Tonttila (2006) points out that all mothers experienced complicated emotions. They experienced anger, mourning, fear, sadness as well as love and bonding. Additionally, mothers experienced that persons taking care of their child and their relatives' support had significant meaning for their coping. Furthermore, the support they received from the social environment was essential. Another important helpful group was the families who were in the same situation. However, the study also demonstrates that life situation among the mothers varied. The mothers with a child with intellectual disability were less stressed than mothers with an autistic child. A few mothers claimed they did not get enough help and had several problems with taking care of their child. The same mothers had still the same situation when their child was later a teenager. These mothers were very exhausted since the situation had remained quite the same.

As a conclusion, all mothers pointed out that the support for the family had significantly decreased after school started. The meetings with school were so rare, that parents felt that it was not possible to get enough support for their parenthood even the dialogue with teachers was not problematic. (Tonttila 2006).

Lehtolainen (2008) researched the home-school interaction and how it should be steered towards exchanging practical ideas. The research consisted of 13 schools, 32 homes that participated and 501 writings and interviews. A practice period was carried out in a small pre-school environment in 1997. The study was conducted in an unnamed town. The emphasis of the study is on the handling of everyday life information in the schools. Teachers and parents of typical children have somewhat different understandings of home-school collaboration. The forms of contact in use are generally seen as biased. Both school and home are longing for consistency and honesty in communication but understand it differently. Difficulties and failures that individuals face in communication

and social interaction are quite usual, such as different view on what kind of communication there should be. The forms of communication are also seen as blocking the successful home-school interaction.

Koegel & LaZebnik (2004) studied various communication methods between parents and teachers of children with ASD. The focus is on children in special education and their parents' participation and involvement. Parents know their children best and they need to master a whole new set of parenting skills as they are usually the most consistent people in their child's life. Koegel & LaZebnik note the parents are the most natural advocates also to their children's school. Parents are emotionally invested in special needs of child's welfare, even after the school years are over because their children might still be living with them as adults.

It is significantly important to understand and address the needs of parents regarding to communication and its methods and styles. (Strom & Strom 2002). This is, according to research, important and I want to explore how parents actually experience communication with schools.

## 1.2 Objective of the study and research questions

This research aims to bring out experiences of parents with children with ASD diagnoses, on school-parent communication systems and support services. Focus is on the experiences of parents with adolescent aged 17-20 with ASD, in Finland and in the U.S.

- A) How do parents maintain involvement in their child's education services, such as education plan, special education services and behavioral interventions.
- B) What kind of obstacles do the parents face in communication? What makes the communication successful.
- C) What kind of communication methods do the parents in both countries use, while in contact with their children's school.

### 1.3 Methodology

The research used the narrative analysis method, and data was collected via narrative interviews with four mothers with teenager children (at least a decade of an experience with school) with an ASD diagnosis. I compare these four families in two distinct cultural and educational settings. Narrative analysis is chosen to catch their personal story and give them the possibility to share their experiences. The mothers are given a voice to tell their stories in their own words. In this chosen method, the conversations could also be a therapeutic and therefore revealing too, because it is not always easy to go down the memory lane, especially when there have been difficult and sad events.

Theoretically speaking narratives are stories of experiences that can be strategic, functional and purposeful (Riessman 2008:8). People tell a story to remember, argue, justify and even persuade the audience. Individuals turn to narrative to reassess memories. In other words, narrative provides ways to make sense of the past. First, narrators can argue with stories. For example, lawyers construct narratives in courtroom settings and place facts and characters in space and time to give order to what has already happened to persuade judges and juries to provide an advantage for their clients. All storytelling tries to convince audiences that may be skeptical and explain to them what has occurred and lay out why things are the way they are or how they have become the way they are. They lay out how they experience certain events and discuss these experiences. Social workers use interviews to construct stories about clients to persuade governmental bodies. Finally, narratives can also mobilize us into action for progressive social change. (Riessman 2008: 8-10).

According to Trahar (2009) and Andrews, Squire & Tambokou (2008) narrative analysis is based on the fact that individuals try to give a meaning to their lives through stories. Narratives are collected by using different methods and analyzed in numerous ways. The differences between the methods, structural narrative analysis (Labov 1982) and narrative analysis (Polkinghorne 1995), are in the way participants are chosen, narratives are gathered, how the data is collected, interpreted and analyzed. Also, the same applies in the fictionalized representation (Clough 2002) and dialogic/performance analysis

(Riessman 2008). Furthermore, the background of the researcher has its influence: whether it is for example psychology, psycho-linguistic, linguistics, sociology or study of the arts.

Thus, there is even more obligation on the researcher to articulate transparently how he or she gathered and analyzed the data. Major way of gathering verbal narratives is the narrative interview which has similarity to broader definitions of semi-structured and unstructured interviews. Narrative interview may also be viewed as a collaborative activity in which the researcher shares the impact on him or her of the stories that are being told. Different stories may emerge through such an interactive process, stories that are co-constructed (Chase 2005). According to Riessman (2008: 57) thematic approach is suited to an extensive range of narrative texts. Thematic analysis can be applied to stories that develop in interview-type conversations and those found in written documents.

The advantage of this collaborative effort for my study is that I share the impact of the similar experience. Because of my own background as raising a son with ASD both in Finland and in the U.S, I know how parents can be involved in schools vary. I had experienced that schools provide more involvement opportunities in the U.S than in Finland. Also, in elementary school teachers communicate better with such opportunities as in middle school and in high school in both countries.

#### 1.4 Motivation, scope of the study and limitations

I have a 21-year-old son with autism and I work in an organization which creates services to people with autism, to their families, and to other organizations. Having a child with ASD affects every aspect of life and parents make observations of their child all the time. Over the years the societal understanding of autism has increased, but in practice there's still a whole lot of work to be done. For children with ASD there needs to be understanding, continuous support and parents and teachers should have collaborative relationships.

Furthermore, I believe that having personally experienced that communication between schools and parents is vital, I decided in this study to focus on models and methods of communication between home and school. Having lived with an ASD son both in Finland and in California I noticed and experienced, that in California there are far more communication methods being used between home and school than in Finland. But at the same time these methods do not apply all over the world or even every place in the U.S. The two comparable countries for this study chosen are Finland and the United States, California.

### 1.5 Outline of the thesis

This thesis is composed of six main chapters: this first chapter is an introductory and a review about previous studies on the theme. This chapter also includes description of research questions of this study and chosen research methodology. Chapter two specifies the target group, interviewees and topics. Chapter three consists of deeper account of different scientific diagnoses, which are related to autism. These diagnoses create the theoretical basis of several systems and methods which are used when working with autism environments.

Chapter five takes the logical step which arises from previous chapter: it describes different communication - and assessment methods and legislation that concerns the practical work with autistic children and their parents; especially in school and other education environments.

The sixth chapter is the thematic analysis of this study in practice, which is based on the guidelines described and chosen in chapter two. The last chapter summarizes the observations and has also some suggestions about measures and further studies around the theme.

## 2 INTERVIEWEES AND TOPICS

The interviewees were two Finnish mothers with adolescents with ASD and two American mothers with adolescents with ASD. Participants were all mothers because only the moms showed up, as mothers mostly take care of their children, still these days, and fathers were more absent as they can't be involved with school because of their work. According to Vincent (2002), mothers especially would like very much to be involved and part of their children's education.

The Finnish interviewees were recruited through member associations of the Finnish Association for Autism and Asperger's syndrome in Finland. The American interviewees were recruited through the Modesto School District located in California, U.S.

All participating mothers had a child currently attending or having graduated from normal secondary school or high school. All the participants voluntarily took part and were willing to share their experiences and perceptions. Participants took part in discussions that lasted for about two hours in settings that participants chose where they felt comfortable at, in the park and in a coffee shop. Two separate discussions were conducted 13<sup>th</sup> of June in 2014 in Beyer Park, Modesto, California, U.S. and 2<sup>nd</sup> of July in 2014 in the Starbucks coffee shop in Modesto, California, U.S. The discussions in Finland took place 10<sup>th</sup> of March in the Coffee House coffee shop in Vantaa, Finland and 5<sup>th</sup> of April in 2015 in a Coffee House coffee shop in Helsinki, Finland. The Finnish mothers' interviews were conducted in Finnish and translated in English by the author.

Interviewees and how they are coded in the chapter six and in the list of sources:

Sonja, 45, with a 17-year son with ASD, Helsinki, Finland	Finnish parent
Tanja, 46, with a 19-year old son with ASD, Helsinki, Finland	Finnish parent
Laura, 45, with a 20-year old son with ASD, Modesto, CA, U.S.	American parent
Allison, 42, with a 17-year old son with ASD, Modesto, CA, U.S.	American parent

Firstly, the interviewees answered questions on their biographies and the biographies of their children. These questions were about ages, years and types of schools and diagnoses of the children. Parents also provided their child's major life line of the events accrued. It was important that their story was in chronological order.

The questioning, time and movement of the conversation were directed very heavily by participants and their desire to discuss issues relevant to communication between home and school. The discussions of the four interviewees were arranged under four major themes: positive communication, negative communication, communication methods and different meetings. Comparison was then made between Finland and the U.S, California. The discussions were voice recorded and later transcribed to finalize the narrative data analysis. These intertwined questions were used to guide the direction of the discussions and keep the conversation moving forward:

- 1) How does the communication between parents/children and schools happen on a regular basis, daily/weekly? How often are you able to visit the school and observe?
- 2) How and who do you know to contact in school with your questions and concerns?
- 3) How consistent and open is the communication? Are you for example aware of issues in school that are important regarding your child? Is your possible input welcomed?
- 4) How do you model the strategy the school uses with your child? Is it possible to implement it in use with children also in home?
- 5) Are there any kind of parent support groups provided by school? How do you volunteer/get involved in school's activities?
- 6) Is there any written plan and/or a review of your child's progress?

### 3 DIAGNOSES CONCERNING AUTISM

There are many different terms that are being used to describe autism. They have included autistic-like, non-verbal, developmentally delayed, autistic tendencies, high-functioning and low-functioning (Taylor 2011). The combinations of signs and symptoms in autism are endless. The important thing is that all children with autism are different. What works for one may have zero effect on another. The symptoms emerge in early years of life and a child is usually diagnosed within the first three years after birth. Some children may still not be diagnosed until years later when they enter school. Unfortunately, if a child has late-occurring social deficits or difficulty playing with others, they are usually too old to take advantage of early childhood intervention services. For this reason, a child needs evaluation to enter the special education system. (Igafo-Te'o 2010).

The American Psychiatric Association (APA) has created a system of classification for conditions which affect how the brain functions. The degree of difference varies from severe to mild and intelligent. Severe ASD was and still is today called Autism Spectrum Disorder (ASD) according to the old classification. However, a milder form of ASD is known as Asperger Syndrome (AS). Other people with ASD fit into the mild category which used to be called Pervasive Developmental Disorder not otherwise specified, typically shortened to PDD-NOS. (Taylor 2011: 22).

As of May 2013, the classification system of the APA, in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), removed the three main subcategories, ASD, AS and PDD-NOS. Everything is now called Autism Spectrum Disorder (ASD) in the U.S. Psychologists and psychiatrists are now using these diagnostic criteria as they appear in DSM-5 when evaluating individuals for this developmental disorder. (DSM-5(TM) 2013).

### 3.1 Autism Spectrum Disorder (ASD)

The Dictionary of Psychology (2015) classifies ASD as follows:

a behavioral syndrome of neurological dysfunction characterized by impaired reciprocal social interactions, impaired verbal and nonverbal communication, impoverished or diminished imaginative activity, and a markedly restricted repertoire of activities and interests relative to age.

Autism is defined as one of the most pervasive developmental disorder that affects a person's ability to communicate, socialize and respond to the environment (Willis, 2006). There are differences in variety and intensity of special interests in ASD. The degree of difference of characteristics varies from mild to severe. (Taylor 2011: 22).

Koegel and LaZebnik (2004) discussed with thousands of parents of children with ASD over the years and reported that getting the news of the autism diagnosis is horrific, terrifying, depressing and stressful. Osborne, McHugh, Saunders and Reed (2007) reported:

levels of stress experienced by the parents of children with ASD are enormously high, compared to those experienced by parents of children with almost any other type of disability or health problem.

Likewise, Tonttila (2003) reports that the mothers with children with intellectual disability are less stressed than mothers with autistic children. Having a child with an incurable disorder is very challenging. Commonly all parents or caregivers of a child with autism go through an emotional rollercoaster when thinking that their perfect child has a disability that will affect almost every aspect of his or her life.

Willis (2006) notes that ASD is a neurological disorder and people in the spectrum all experience difficulties in three primary areas with delay with communication, difficulty in social interactions and repetitive behaviors and body movements known as the triad of impairments. The impact of these three will vary as every person with autism is an individual. Some children will outshine in certain areas, but they all have strengths to be

cultivated. Additionally, they often have super sensitive senses and may be extremely troubled by noise or brightness.

People with ASD have poor social perception ranging from being withdrawn to appearing unresponsive or simply not fitting in. They can become socially and emotionally isolated because it is very difficult for them to establish and maintain relationships. ASD affects their social life including education in many ways because they are lacking social skills. Autism becomes a factor also in the ability to express emotion and understanding how others think and feel. (Willis 2006). Therefore, people with autism may seem insensitive of other people's feelings which can lead to problems for instance when making friends. As people with ASD get older, they usually become more comfortable being around other people.

According to the Finnish Association for Autism and Asperger Syndrome (Autismi- ja Aspergerliitto) the number of people in Finland who are in the autism spectrum is approximately 80,000 (2015). The reason it is more common now than it was in the past might be due to better awareness about symptoms. That has led to greater efforts in diagnosis. It is not clear if the increase is due to a broader definition of autism, or if there has been a true increase in the number of autism cases. Over the past decade awareness and understanding have increased greatly.

Autism Speaks (2015) reports that statistics from the U.S. Centers for Disease Control and Prevention (CDC), suggested that in the U.S. one in every 68 children and one in every 42 boys is diagnosed with ASD. ASD affects boys four to five times more than girls. According to estimates 1 in 189 girls are diagnosed in the U.S. More people than ever before are diagnosed with ASD today. Statistics state that the prevalence of autism has increased 10 to 17 percent each year in recent years. Altogether autism affects over 3 million American individuals and tens of millions worldwide. Although there has been a significant amount of research conducted on ASD, there are still no final conclusions on what is causing the increased diagnosis worldwide. Many researchers suggest that improved diagnosis methods are reasons often to be considered.

To understand better how the Autistic mind works Taylor (2011: 22-23.) has an enlightening computer analogy, in where human beings are compared to computers. It shows how the brain of a person with ASD is hard-wired differently to the rest of us. The difference in thinking patterns can be imagined as ASD being Apple computers, and “neuro-typical” people are imagined as being Windows computers. A Windows-based computer can run any program designed for the Windows operating systems and Windows-based computers can communicate with each other.

The small percentage who are Apple computers will run any program that is written for Apple operating systems. But Windows computers cannot understand Apple programs and vice versa. Nothing happens if you try to run programs written for Apple computers on Windows-based computers. It does not matter how many times you try to run the Apple program on the Windows computer: the error message just pops up. Most importantly, it will never work, and the computer might even crash. This kind of an incompatibility runs in both directions. (Taylor (2011: 22-23).

We tend to make assumptions based on our Windows thinking and experience and get irritated when the Apple-based person does not respond the way we assume. We cannot change the fundamental brain operating system of people with ASD or people who don't have ASD. Many people with ASD have awoken to understand that there is a difference in thinking patterns between them and what the rest of us might call “normal” people. (Taylor 2011: 22-23).

### 3.2 How Autism was discovered - Asperger Syndrome (AS)

The diagnostic term Asperger Syndrome is based on the perceptive descriptions of a Viennese pediatrician Dr. Hans Asperger. He discovered that some of the children referred to his office had very similar behavior and personality characteristics. Asperger Syndrome, with the unusual outline of abilities, has possibly been a significant and an essential characteristic of our species throughout the evolution. Both in Europe and in America the psychological study of childhood had become an acknowledged and ever-

increasing area of science by the mid- 1940s. Considerable progresses in descriptions, theoretical patterns and assessment methods had been made but Asperger could not find a clarification for the small group of similar and extraordinary children that he found entrancing. He suggested the term *Autistische Psychopathen im Kindesalter*. That is, personality disorder in modern English which is a description of someone's personality rather than a mental illness such as schizophrenia. (Attwood 2007: 12-13.)

Asperger wrote an extremely insightful explanation of the children's abilities and difficulties as he was obviously fascinated by children with autism spectrum disorder (Asperger 1991). The children's social reasoning and concept of navigating personal friendships were delayed along with social development. He observed that their social abilities were quite uncommon at any stage of maturity and they had difficulty making friends and were often teased by other children. The children also had deficits in verbal and non-verbal communication, particularly the conversational part of interaction. The thoughts and certain obsessive-like interests would get stuck in their mind and dominate their time. Asperger observed that the children had specific learning problems and struggled maintaining attention in lesson. He described noticeable clumsiness in coordination and walking and monitored that some children were extremely sensitive to specific sounds, smells, textures and touch. Normally they also needed more support from their mothers with self-help and organizational skills. (Attwood 2007: 13).

Asperger describes the characteristics can be identified in some children as young as two to three years old. In general fathers of such children seemed to share some of the personalities of their child. He explained that the condition was probably due to genetic or neurological factors rather than psychological or environmental matters. In his early and following publications and a recent study of his patient records for children he saw over three decades, it is evident that he considered autistic personality disorder as part of a natural variety of capabilities that blends into the normal range (Asperger 1991; Asperger 1979; Hippler & Klicpera 2004). Asperger theorizes the disorder as a life-long and unchanging personality type. He did not monitor fragmentation and disconnectedness that appear in schizophrenia. Some of the children had extraordinary gifts that could lead

to productive employment and some could develop lifetime relationships. (Attwood 2007: 13).

### 3.3 Pervasive developmental disorder not otherwise specified (PDD-NOS)

PDD-NOS became the diagnosis applied to children who are on the autism spectrum but who do not entirely meet the criteria for ASD or AS. It is used for someone who has quite mild symptoms or has some but not all characteristics of autism. For example, a person may have severe or extensive autism symptoms in one core area, like social deficits. However, the same person may have mild or no symptoms in another core area, for instance repetitive behaviors. Defining features of PDD-NOS are just like with ASD, significant challenges in social interaction and language development. But PDD-NOS is a rather new diagnosis and has only existed approximately 15 years. Therefore, some physicians may use it inaccurately or the term may not be familiar to them at all. The term PDD-NOS is included in DSM-5 to cover cases where there is clear deficiency of social interaction, communication or stereotyped behavior but which do not fully meet all the signs and symptoms of autism. (Autism Speaks 2015).

## 4 MODELS OF COMMUNICATION IN SPECIAL EDUCATION

All children with autism diagnosis, regardless of their age, have problems in communication especially in school. Communication is an essential supportive tool for their overall development and for their success in everyday life. Moreover, communication is examined as a key component when we study parental involvement. It is also important to find out the parent`s participation goals and interests with each provided service in special education for the children and families.

### 4.1 The importance of communication

Services should focus in every detail and aspect on the individual needs to increase parents' different communication methods, involvement and active ongoing engagement. Rather than services concentrating on general educative activities and traditions. (Kroth & Edge 2007: 17). Parents' important role is to help improve their child's teachers' willingness to set boundaries and explain what is expected from their children (Ouimette, Feldman & Tung, 2006).

To communicate better between home and school parents are willing to be involved in their children's special education programs in more nontraditional ways, such as decision making regarding their children, educational services delivered to their home and parent trainings focused on working with their children with special needs (Kroth & Edge 2007: 16).

Children with ASD diagnosis can present challenging behavior due to their partial inability of adaptation in frustrating situations in school settings. Many have also limited language skills. Consequently, their communication and behavior need extra support across different settings. If parents do not receive adequate information from the school about their child's challenging behavior, it is impossible for them to resolve same kind of issues proactively at home (Strom & Strom 2002).

Carothers and Taylor (2004) point out that children with autism are likely to have better adult outcomes if they know how to conquer a variety of functional daily living skills. However, if these skills are to be generalized and maintained they need to be taught repetitively by different individuals both at school and in the home. Therefore, teaching and learning new skills come down to importance of collaboration between home and school.

Children with autism may not completely understand the facial expressions or tone of voice or gestures given from teachers or their peers during the communication. Therefore, participating in class and understanding the teachers is challenging. They also find it very difficult to cope with changes to their daily schedule and struggle with subjects that use abstract ideas. The barriers they face are social, so the support they need from educators and parents cannot be determined just by a medical model of disability. (Baron-Cohen 2008).

#### 4.2 Special education laws in Finland and in the U.S.

In Finland according to Ministry of Education and Culture authorities try to guarantee educational support to address the special needs students with mild to severe physical or intellectual deficiencies or hearing or visual impairments. Those students might be slower, have dyslexia or autism diagnosis. The fundamental principle of Finnish education is:

to provide equal opportunities for learning and growth to every pupil or student. Support for learners plays a key role. This entails removing barriers to learning, physical, attitudinal or pedagogical, early intervention and support and welfare.” (The Finnish National Board of Education).

The overall spirit of Finnish Education laws is that all people must have equal access to high-quality education and training. The same opportunities to education should be available to all citizens despite of their ethnic origin, age, wealth or where they live.

In most countries, legislation provides that people with special educational needs, including ASD, should have the same opportunities and rights as all people. In the U.S all students with disabilities are guaranteed free public education in the least restrictive environment possible. Students must be also provided a Free Appropriate Public Education (FAPE) which prepares the students with disabilities for further education, employment and independent living (FAPE). It is also important to take a note that the “No Child Left Behind” (NCLB) policy encourages the establishment of parent partnerships with schools (No Child Left Behind).

Special Education refers to the education provided to students with special needs. In the United States special needs include cognitive, physical and developmental disabilities, learning disabilities, socio-emotional and psychological issues, hearing and vision impairment and language differences. (Disabled World 2015).

In the U.S. the 1997 Amendments to the Individuals with Disabilities Education Act (IDEA) and the 1999 Final Regulations have brought about several changes in policy concerning special education. Above all IDEA requires school personnel to develop a Functional Behavioral Assessment (FBA) and Behavior Intervention Plan (BIP) for students with disabilities (Fad, Patton & Polloway, 1998).

IDEA governs how states and public agencies provide early intervention and special education or related services to children with disabilities. The law is designed to meet the unique learning needs of eligible children and adolescents with disabilities from preschool through age 21. IDEA 2004 aligns closely with the No Child Left Behind Act, helping to ensure equity, accountability, and excellence in education for children with disabilities. (Kroth & Edge 2007: 190).

IDEA requires that if a child’s behavior is affecting his or her learning or that of peers, an IEP meeting should be requested so that a BIP or an FBA plan can be carried out. It clarifies Congress' intended outcome for each child with a disability and indicates that parents can advocate to ensure appropriate educational services for their children. Parents or any member of the IEP team can request the deliberation of an independent educational

evaluation in determining eligibility for special education services. Preferably, teachers and other school staff advocate on behalf of children with disabilities. (Trainor 2010: 35).

#### 4.3 Meetings

Tonttila (2003) points out that because school-parent meetings are too rare it is not possible for the families to get enough support from school.

In Finland there is a meeting called “vanhempain vartti” (“parents’ quarter”) which is a short meeting between a teacher and a parent that is supposed to last only fifteen minutes. Finnish equivalent for an IEP is called ”henkilökohtaisen opetuksen järjestämistä koskeva suunnitelma”, HOJKS. It is imposed in the Basic Teaching Act of Finland and instructed more accurate in the statutes of National Board of Education. (Perusopetuslaki 17 §, 642/2010).

In Finland, Wilma, a web-based interface tool is used mostly when educators in schools communicate with students and parents in real time if necessary. Teachers, students and parents can write to Wilma messages, announcements, mark absences and grade students. Students can also check their schedules and register for courses in Wilma. It is considered to help communication between home and school (WILMA).

In U.S. parent/teacher meetings and team meetings, such as IEP, include parent, school and the student. IEP meetings can be held four times a year in an Elementary School and in Middle School and an annual IEP is held in High School. Review meetings and Emergency autism meetings are held right away if there are behaviors that are inappropriate in a school setting, for example tantrums. IEP will be discussed more closely in chapter 5.4.1.

In U.S. there are other important meetings between school staff and parents, traditional and informal, such as “Open House” and “Back-to-School Nights”. A Back-to-School Night is held within a month after school has started. It gives information to parents about

the upcoming school year. An Open House night is held towards the end of the school year. The teachers are displaying the most important projects the students have accomplished during the school year.

In Finland it's called "Avoimet Ovet" (Open doors) which serves the same function as the schools in the U.S. Also, in U.S. Summer schools help maintain the goals with children with ASD. Summer schools are usually not organized in Finland; for there is no legislation to rule or encourage for them.

Explaining to parents what tools are used by teachers is the key for preventing negative things from happening with the children with ASD. Federal law in the U.S. requires school professionals to invite parents to join them into the planning meetings for their children with disabilities (IDEA).

A study with 217 parents with special need children conducted in the U.S. by Turnbull et al. (2011) show, that the most popular communication method for parents to approach educators is by telephone or face-to-face contact.

According to Hornby (2011: 79-96) there are a few common strategy options for parents to communicate with staff at school, eight methods are included in communication:

- IEP, which is held at least once a year and can be requested by any member of the IEP team to be held more frequently to set goals and objectives together.
- A weekly/monthly meeting, which are held to share information, concerns and ideas as well as show children's work done at school to parents.
- E-mail Correspondence, which is very useful and a common method for both parents and teachers to quickly checking in. It is useful for parents to let teachers know of their child's absences. E-mail is a good possibility for schools to send newsletters instead of printing them out and sending print copies to parents' home.
- Parent/teacher conferences, which are a useful way of communicating between home and school and establishing good relationships.

- School News Letters, which are general to all parents or more specific to the parents of children with special needs. Newsletters are sent out regularly twice or four times in a school year and can include notices of events, updates on projects or invitations to volunteer at school.
- School Field Trips, which is a good opportunity for parents and other family members to join in for school outings.
- Open House, which is a type of informal way to achieve a large possible proportion of parents to come to the school to meet teachers and see displays of student's work, along to look around the school and see classes in progress.
- Telephone Correspondence, which are reported to be used mostly in many surveys because most of the parents are comfortable being in contact with educators by phone and many of them owning a cellular phone nowadays.

#### 4.4 Behavior interventions

One of the most current treatment and communication methods, which teachers and parents are using collaboratively to provide support and help for children with ASD diagnosis, is a positive BIP. This tool is an important part of the ABA, which is a scientific approach used especially in the U.S. attempting to change the target behaviors. (de Rivera, 2008).

These behavioral approaches have received official recognition by the U.S. Department of Health and Human Services in 1999. (Mitchell 2008: 181). There is no similar treatment method to the BIP in Finland. However, the before-mentioned HOJKS is an equivalent for IEP.

#### 4.4.1 HOJKS and IEP

The Basic Education Act of Finland has shaped education policy in Finland. (Pesonen et al. 2015: 171). The Act (642/2010) aims at providing support for students with special needs based on teacher's sole observation, but without receiving official diagnosis. The school professionals are required to provide support and services as soon as the need occurs. (Cameron & Thygesen 2015). This law in Finland mandates that each special education student will have an annual HOJKS, which is used to develop instructional goals for students with special education needs.

In the U.S., IEP is held for students with special education needs between the ages 3 and 21 at least once a year. It can also be requested by any member of the IEP team to be held more frequently. When a request is made by a parent or education staff member, the IEP review meeting is required to be held within 30 days of the request by Federal Law. The object of the review IEP meeting is to discuss and agree any modifications or additions to the IEP document that are mandatory to provide Free Appropriate Public Education (FAPE). This is an educational right of children with disabilities in the U.S. The IEP team shall meet to review student's progress, goals and objectives to develop a Behavior Support Plan (BSP). (Fontana, Carranza & Dimberg, 2015: 48).

Instructional goals and objectives are set to define individually, what a student will learn in school, within a certain period. Concretely that might be for example "to learn 100 new words". These goals and objectives are presented in an IEP at three levels: annual goals, short-term objectives and daily or weekly objectives. The annual and short-term goals are included annually, and the daily or weekly objectives are typically covered within daily lesson plan. Theoretically, the three levels of objectives insure that the educational program for a student is appropriate. Goals and objectives enable educators to plan what and how to provide instruction for students over a given period. (Rusch, Rose & Greenwood 1988: 90-91).

#### 4.4.2 Applied Behavior Analysis (ABA)

ABA is the one form of the treatment and intervention for autism diagnosis in the U.S. This behavior intervention program has scientific evidence to show that it makes a positive difference. This treatment tool is used to analyze a child's behavior, to understand what the fundamental motives of the behavior are. Then there are better chances to find out what changes are needed to make to help the child come up with something more suitable and appropriate behavior. These techniques reduce inappropriate behavior and increase learning, improve social communication skills and appropriate social behavior. (Taylor 2011: 101).

According to Koskentausta, Sauna-Aho & Varkila-Saukkola (2013) treatment methods such as ABA are shown to be effective in children and adolescents with ASD, although they are seldom used in Finland. They are very time-consuming treatment methods. The management of severe challenging behavior is based on applying comprehensive rehabilitative approaches in daily life, as well as promoting the interaction and communication skills of children or adolescents with ASD. Several kinds of rehabilitation methods are recommended in Finland, although there is very limited scientific evidence on their efficacy.

The Finnish National Agency for Education has not given any national specifications or recommendations about the use of ABA, or other similar inquest. Schools arrangements for special support which are mentioned in curriculum, for example planning the personal pedagogical survey, are settled locally in municipalities (Palmqvist 2018).

#### 4.4.3 Behavior Intervention Plan (BIP) in the U.S.

Children and adolescents with special educational needs are defined with variety of disabilities with mental, physical, emotional or behavioral problems. These deficits prevent them from taking full advantage of regular classroom. Therefore, there are professional assistance, learning aids, extra care, special settings and clearly specified

teaching strategies. (Mitchell 2008: 2-3). Once the parents or educators have identified the deficits named above, major challenges accompany aiding the children and adolescents with their diagnosis and disabilities. BIP is provided to help to cope with school and home environment, as well develop skills to be able to integrate successfully. (Quinn, Gable, Rutherford, Howell & Hoffman 1998: 8).

After the IEP team, of which school professionals and parents are a part, has conducted an FBA, the information gained from that procedure should be used to develop a BIP for the child with autism. (Quinn et al. 1998: 4). The reason and structure of this plan is to identify and describe the problem behavior, clarify why it happens and define the strategy of how to support the change in behavior. Effective support plans consist of multiple interventions or support strategies such as positive BIP which teaches and supports new replacement behaviors, decreases the inappropriate behavior and as a result enables common improvements in the quality of life of the individual and his or her family as well as members of the IEP team. (Quinn et al. 1998).

The BIP starts from the assumption that parents can assist in the identification of appropriate intervention techniques and replacement behaviors. This plan needs to be implemented with consistency and fidelity across people and different settings. This means that parents need to be trained in the implementation of the intervention techniques, so they can implement the same intervention at home. This component is crucial to the success of a BIP. As parents spend more time with their children than teachers do, they are just as likely to see their children engage in problematic behavior. If everyone in the child's life is implementing the same intervention techniques, the child is likely to learn the replacement behaviors at a faster rate. (Fielder, Simpson & Clark 2007: 239-242).

The BIP claims that it is very important for parents to be involved in the assessment procedures. If a child displays problematic behavior parents can provide additional background information on child's behavior as it helps to understand the function of the behavior. Parents can also provide very important access to non-school environments where they can see their child's behavior in different contexts. Giving information on

their child's behavior intervention development and intervention implementation is vital. Therefore, parents are important observers and data collectors when solving their child's behavioral issues.

#### 4.5 Parental involvement in Finland and in the U.S.

In the Finnish education system, the policies do not require parents to oversee their children's education: they are expected to have a relatively passive role. But parents are expected to engage actively in homework and support the success of their children. Karila & Alasuutari (2012) and Sahlberg (2007) claim that a trust-based school culture started in Finnish society already in the early 1990s and parents and students genuinely trust and respect teachers and schools. Students are compelled to be accountable for their own learning process and considered to be independent at a young age.

According to Karila & Alasuutari (2012) Finnish parents appreciate collaboration between home and school. Traditionally parental involvement is aimed to assist teachers at school events and some parents are also involved through PTA. Additionally, a few parents are participating in school decision making by sitting on the school board. (NCEE 2015).

Parental involvement is more than attending to formal meetings at school. Jeynes (2005: 245) defines parental involvement as parental participation in the educational processes and experiences of their children at school. It is important to notice that parental participation takes many forms: two-way communication between home and school, supervision of homework, attendance in parent/teacher conferences and classroom volunteer or teacher's aide. (Watson, Sanders-Lawson & McNeal 2012: 42-43).

According to Hornby (2011) parental involvement is known to improve children's attitudes, behavior and attendance at school. Furthermore, it improves parent-teacher relationships, parental confidence and satisfaction with parenting. Parents are the primary influence in children's lives. In providing the ideal education, collaborative partnership

between various school professionals and parents is vital. In many countries the governments have recognized parental involvements role in enhancing educational outcomes. Strom and Strom (2002) report that parents' proactive involvement in their child's education decreases the rates of suspensions and academic failure.

In the United States a key factor in enriching educational outcomes has been the "No Child Left Behind" (2001) policy which encouraged the founding of parent participation with schools. As of December 2015, the policy is no longer valid and federal government has replaced with Every Student Succeeds Act (ESSA). (Every Student Succeeds Act)

Grant and Ray (2010) emphasize that schools value parents' and educators' collaboration. Schools provide regular communication opportunities for parents and teachers, such as parent-teacher nights. Schools accept parents easily joining the PTA meetings, volunteering in the classroom and raising funds. They feel that numerous communication practices encourage parents to be involved in the relationship with the educators. Moreover, Grant and Ray (2010) show that it is important to focus on other elements than only on traditional activities.

Many elements influence parental participation. Parent/teacher conferences are an important platform to discover of how much the goals and agendas of parents and teachers can differ. Teachers have their own goals for parental involvement. Their emphasis is in homework, increasing children's achievements, nurturing environment and raising funds for school. (Hornby 2011: 2, 18).

#### 4.6 Parental participation in Special Education

It is fundamental for children with ASD that teachers and parents set goals together. It helps children make progress both inside and outside of the classroom. Therefore, parents play a key role in their children's education. The guidance and support from the educators are essential to the parents of children with autism in managing their child's challenging

behavior. Research evidence show that when support is provided, both children and parents benefit from it. (Mitchell 2008: 75).

Kautto & Martikainen (2012) found that both educators and parents are willing and showing interest for an active collaboration for the benefit of children with special needs. Parents require teachers to cooperate and at the same time teachers feel the demand from the parents for an effective ongoing two-way communication. However, parents with children with special needs feel anxiety by educator's behavior and attitude towards them. At the same time, educators don't feel that they are causing stress and anxiety to the parents. Parents are aware that the teacher's job is to provide educational structure and teaching and the parent's job is to help their children with their schoolwork.

Parents with children with special needs are more inclined to be active in parental involvement events in schools due to their children's daily struggles with their disabilities and diagnosis (Eccles & Harold 1993). For that reason, it is vital to involve parents into ongoing hands on effective education participation with children with disabilities (Hornby 1995, Seligman 2000).

IEP requires that parents need to be involved of the implementation of the plan. Yet, at the same time there are obstacles for efficient parental involvement. There may be disagreements between educational professionals and parents with special need children. For instance, teachers require parents to assist their children more at home of what children are working on at school. In the same time, parents are expecting more support academically for their children from their teachers. (Hornby 2011: 17).

Benson & Dewey (2008) state that the stress associated with parenting on a child with ASD diagnosis is greater than for any other childhood condition or developmental disability. It should be strongly supported to reduce conflict between parents and the school professionals and thereby reducing the stress in the parents. The goal of constructive parental collaboration cannot be met with the lowest possible standard. Parents of children with autism are often greatly involved in their child's school:

especially on their ongoing behavioral and social interventions. There should be more school meetings devoting to the students' strengths rather than meetings focusing on their problems.

Collaboration between home and school setting is essential to parents with children with autism. According to Parsons (1999), parents can be hesitant to go into schools when their children are showing challenging and inappropriate behavior. They are anxious of receiving more negative information involving their child. In fact, studies show that when children have developed a reputation for being challenging, there are usually a negative relationship between parental involvement and children's behavior problems. (Parsons 1999: 58). Typically, the more troublesome the behavior, the less parents tend to be involved with the school. Disagreement between parents and school is nearly unavoidable once behavior problems become so difficult that schools must begin to consider suspension or even removal. It creates clear barriers to important parental involvement. (Parsons 1999: 81).

## 5 THEMATIC ANALYSIS

### 5.1 Introduction

This chapter contains the thematic analysis along with the discussion of the narrative data of the participants with children with ASD diagnoses. The analysis is divided into four different themes according to personal aspects of the participants as they evolve from the narratives. The analysis identified different strategies that parents might take to make communication better between home and school for the benefit for their children's educational outcome. The focus was on finding out how parents experience communication and what impacts positively in communication for parents so that they can also trust the teachers' ability to influence on their children with autism. Likewise, what barriers were limiting them to reach successful communication with their child's education providers.

Thematic analysis was supposed to bring out material that will help to answer the research questions by examining parents' observations and involvements of the communication between home and school. The collected data consists about communication of the parents: where they felt that they succeed and where they proceed problems. What difficulties they faced and what were the facts that made communication difficult with educators. The focus was to discover what kind of communication methods were in use in Finland and in the U.S.

### 5.2 Theme one – Positive Communication

This chapter consists of positive experiences that parents shared in communication with educators. In both countries the parents who participated in the research described email as the ideal method of communication between home and school. All four participants experienced that when there is a lot of communication between home and school via email, parents feel that they are on the same page with educators. They sense the support from teachers and therefore they know they are not alone with their children with autism.

It is also important to help parents to lower the stress they have because of the special challenges they face with their children with ASD.

In Finland, participants use Wilma the most for emailing the teachers, but they didn't have examples of encouraging and positive content and tone of the emails. Wilma worked as a good method but the participants didn't feel they got much needed support through communication by email. In the interviews it was said that in Finland Wilma is the most general way of parents and teachers to correspond.

Parent 1:

I usually contact the independent teacher of the subject in which the problem comes up through Wilma. Some of the teachers don't have time to respond right away but most do respond and give an update of my son how he's doing in class but I don't feel I get advice how to help him.

In U.S. the participants seem to have a more positive attitude towards parental involvement and collaboration between parents and educators.

Parent 3:

Both of his teachers were wonderful and very helpful, and they would tell me (mom) what kind of a day he would have by emailing me or telling me when I sometimes picked my son up.

Participants in the U.S. also expressed that communication is very good with most of the Special Education Teachers. Parents felt that the greatest progress happens with their children when the lines of communication are open and there is lots of communication. This situation creates the feeling that there is a lot of support too. Parents realized that when a child does the most remarkable changes socially, there is a lot of communication between the principle, autism staff and parents. These parents also commented positively on such school staff who focused on a child as an individual and discussed about his/her individual progress and did not kept comparing him/her to anyone else.

Parent 4:

When I had communication through email with all four teachers in Middle School and as soon as they let me know what is going on, I was able to address it at home and with the autism team and they would come to conclusion. That's when my child would do very well.

Parent 3:

When teacher said to me: "I really like Nick. He is very smart, and I like his sense of humor". It tells me that she really cares about my son as a person. That is an amazing feeling.

Parent 4 below stated that they received an aide for their child with ASD and things started to go better with him. The aide had lots of communication with parents and a good share of it was via email. When lines of communication were open the biggest development was happening to their child.

Parent 4:

All you have to do is get to know your client in person. Listen to them and get to know the triggers. That's when you can really make progress with the child.

Parent 3 below believed that a great deal of their child's success was an outcome of great amount of communication.

Parent 3:

We always communicated with his teachers and we were always willing to work with his teachers. Whatever behaviors came up with his teachers, we were willing to work them out and we always left the lines of communication open.

### 5.3 Theme two – Negative Communication

The four participants shared also negative experiences and reasons for them which slowed down communication. They felt that when the chemistry between parents and the school professionals does not work it makes communication very challenging. The parents felt that some teachers are not willing to co-operate with them. Another problem was that when the school kept replacing the teachers, parents could never get a good report.

In Finland participants were complaining about the communication when the students were having disruptive behavior. Both participants in Finland experienced that school wasn't doing anything until they were asked to help. Communication via email was the best way to communicate, but it wasn't good enough if it only happened through Wilma. Face-to-face contact is important to have every so often, but if participants wanted to discuss with teachers, they might not have been available. According to Parent 1 some teachers were even having difficulties to carry out collaboration.

Parent 1:

I feel teachers should be more aware of giving meaningful behavior support for my child with autism and making modifications to his core curriculum. But I feel they are not co-operating with me or being on the same side.

In the U.S. one mother also experienced that teachers were not always good about emailing and communication via email and it didn't happen daily. Basically, in the U.S. there is a 48-hour rule in email correspondence, in within you are supposed to get a reply, but that wasn't always the case according to participants.

In Finland participants often felt there is no passion in the school for their child with ASD. That affected their communication relationship with educators. Parents' perception of the teachers is of course important too. One parent felt the lack of passion has a negative impact on the nature of their communication relationship. The parent is stressed and has anxiety if the child with autism is not helped appropriately at school settings.

Parent 1:

I think that the reason why some of the teachers didn't keep in contact with me was that they either didn't know what to do or because they thought it was so difficult and didn't want to deal with it. When they know that the kid has a disability, they don't see them as their responsibility. They see them as some special teacher's responsibility.

In Finland parents also felt that teachers often displayed a lack of knowledge about autism.

Parent 2:

I told the school what we can do, but I'm not an expert here, I'm asking them for advice. Concrete advice. But then they just said they can test him for disability. What does that help?

Only one, parent 3 expressed:

The research teacher though was very good about communicating and she would tell me what kind of a day my son had had. She was really wonderful and was just very helpful. She also used to speak to the child very softly between when teaching in class.

Autistic children struggle with change. Any changes, such as changes from one subject to another. Changes are huge and therefore play important role in a child's life. Transitions are very stressful to an adolescent with ASD. Therefore, they need lots of support with any transition. Communication between home and school becomes vital in times like that when there are lot of changes.

Parent 3:

My son Nick told me the aide isn't doing her work and I let the school know. The school replied "*Okay, we'll train her*". But still the same thing was going on until the vice principal went to the class room and within a

day that aide was gone. The principal laid her off because the aide was literally just sitting in the corner reading a book, instead of helping her student. Nick had told me “*she just looks at me and says get busy, sits down and reads a book*”.

This is a very good example of how important the communication is. Nick did not know at this time what he was supposed to be doing and the aide just assumed he was being bad. The mother explained that the aide never bothered to ask if Nick understood the assignment or if he knew what he was supposed to be doing; she would just tell him to “get busy”. This also demonstrates that the children’s involvement in communication is crucial too but of course it depends on the ability of the student. In this case the school had an immediate response, they didn’t postpone it to their next meeting that could be in couple months or longer away. Instead, they laid the aide off immediately.

One critical issue that arose in both countries was an inappropriate behavior support for the students with autism. This impacted negatively on communication between home and school. The participants in both countries expressed that an inappropriate behavior support and lack of reinforcing affects student’s ability to function within the school setting. Children with autism cannot do it themselves without stress and episodes at school environment. Moreover, this lack of support for children influenced parents as well. Parents were themselves having to assure and calm their child, which created even more work at home. It created negative atmosphere between home and school.

Parent 2:

Hey, can you just talk to your son? And tell him that it is a rule and if it is a rule, you have to follow it.

Parent 4:

Whenever my son would have a teacher unwilling to work with him and communicate with us, that’s when he had major difficulties. It was very hard with him.

In both these cases, and in both countries, the participants experienced that the teachers communicated to the parents that they are the ones who need to talk to their children and fix something that was going on instead of co-operating and taking care of the challenges together.

#### 5.4 Theme three – Communication Methods

When there are shared, clear and consistent strategies between home and school, everything seems to work out. People can share success together and that also keeps the lines of communication open.

One Special Ed Teacher told parent 3:

What issues you struggle at home with your child, my job is to help him with those issues at school.

This parent 3 shared that this really lifted a burden from her shoulders. The mother felt they were not alone in this. The communicative support they received from the Special Ed Teacher was huge and helped them tremendously with their child, both academically and behaviorally. Not to mention how much the support helped them to cope with stress. Parent felt that without the Special Ed Teacher's communicative support the situation with their son would have been too overwhelming. When there are consistent strategies between home and school, everything seems to work out.

The strategies in which educators and parents work together and share the child's true needs in daily living skills, also helped to fulfil the IDEA requirement. Use of these behavioral strategies in communication enable children with autism live more independently and successfully even as an adult. Good examples of this is:

Parent 4:

I don't think my son would have been as successful as he has been if I had not had these strategies from the very beginning, used the same system as they use at school.

Parent 4 had experienced as well:

I've been able to implement at home what school has taught and having the same strategies at home and at school, I really do know did help my son a lot.

When both school and home take baby steps, it helps the child to adapt. When visual schedules are the same in both school and home and everyone is following through, progress can be seen immediately.

Parent 3:

The fact that I was willing to bring home what I was been taught at school, helped a lot my son.

Parent 4:

When the reward system, called point system, started with my child, he started to improve very quickly.

Daily data from school professionals and parent's responsibility to review it, makes it possible to help the children to achieve their goals. Especially during challenging times of changes and transitions, daily data is essential for the parents to work out the behavioral issues proactively.

Parent 2:

We don't have an ABA method, but I do receive a daily report from school about the behavior of my child. The responsibility to react on it and especially considering how to react to it at home, is up to parents. But

because it's not a system which is agreed on between us and school, it does not create a strategy. Parents not knowing enough and can't follow through so there's no growth. There should be shared strategies between home and school.

As a result, daily data will also allow school professionals to provide necessary services and modify the program including the behavior plan. Behaviors of students escalate greatly time to time when demands increase. The regular data from school and consistent communication between educators and parents enables to fully benefit from it.

Parent 3:

Another aide in the seventh grade knew exactly what my son needed. And she set up a whole new communication system which allowed her to give points on certain things he was doing right. Like when he was doing something what he was supposed to be doing, he'd got a point. But if he did it independently without being told, he'd get an extra point. And in the end of the day he'd got some points out of some, and then he'd got a piece of candy or something else. And that really worked. She gave him a reward or if he wanted something else instead, like a soda or something. That was excellent communication. And he did very well. After he had this aide and reward system ABA, his grades started to go up. So, he had this aide whole his eighth grade and he ended up with straight A's.

### 5.5 Theme four – Different Meetings

Finnish moms and American moms talked differently about meetings at school. The difficulties parents faced were different. In Finland parents felt that school should have more meetings with parents. Parents felt school professionals should be educating and training them about what methods are used in school so that everyone could use the same tools. Meetings should be more often and more informative, the parents in Finland felt. Sharing info to parents at meetings is the key of how they can do their best at home, when

preventing the child with autism being stressed out. Parents found it challenging to maintain involvement in their child's education services.

Parent 1:

We tried to stay on the same page and attend any school meetings. It was not always easy but that was important.

Parent 2:

If a teacher said you need to do this in a certain way, then I would tell him (my son) let's do it. Like the new math teacher, he got, had a certain way of doing math class. And I said, well that's the way you need to do it. But I didn't talk to his teacher or have a meeting about it with his teacher.

In U.S. the parents were working together more with school professionals than in Finland. Parents took initiative and had learned to advocate for their child. Parents shared they were exchanging knowledge and information regarding their child about his/her challenges at home and negotiated with the school staff about the changes. Participants in the U.S. were satisfied and happy about that. In the U.S. parent-teacher conferences were common option to communicate and were useful way of establishing good relationships. They were informal, could be organized quickly if needed and the meetings could be short.

Parent 3:

IEP meetings, where goals are set, and progress is followed, are the key. The first meeting is always within two months in and proposed goals are given to parents three days prior the IEP meeting, so we know what we can discuss. Both home and school have to be on the same page all the time.

Similar HOJKS meetings in Finland were annual and if necessary, could be held more frequently. The meetings included parents, school professionals and the student. IEP meetings in U.S. they were held four times a year. In U.S. there were also review meetings that were held if behaviors happened and changes were needed. Emergency autism meetings were held right away if something drastically different happened.

In Finland “Parent`s Quarter” was the most common meeting and was held once a year or more often if needed. In both countries informal Open House and Open Doors were held in May to share information to parents as well as show student`s work. Parents were able to meet teachers, look around the school and get to know different projects and programs in which their child was attending.

Back-to-school Night was usually organized to share information in Finland in September. In the U.S. it was typical to share concerns and ideas in Back-to-school-Night. Summer Schools in June and July were only held in U.S. to help maintain the goals the students with autism.

One Special Ed Teacher told parent 3:

I`m here to support you and your child. Where do you want your child to be in 10 years?

Parent 4:

All the people, our whole staff are on your side. There needs to be trust, it is so important. And the communication is major. Kids deal with so many things. Teachers need to let parents know. When teachers are being honest with me (mom) and tell me that`s wonderful. My child`s growth needs to be informed to us (parents).

It`s efficient with the child with autism when every decision is made together. Just as important is to show the parents the supported ground.

## 6 CONCLUSION - GOALS, RESULTS AND PROPOSALS OF ACTIONS

The focus of this research is on the experiences of parents with adolescent aged 17-20 with ASD, in Finland and in the U.S. The aim was at first to clarify the theoretical reasons, mechanisms, methods, diagnoses and legislation concerning parent/home - school/education relationships, with the scope in children with ASD diagnoses, in Finland and in U.S. and how the participants maintain involvement in education services. Secondly, the study was to bring out practical, real-life experiences about the same themes: experiences of parents with children with ASD on school-parent communication systems and support services, obstacles they face and what makes communication successful. Comparisons in experiences in these relations and what kind of communication methods the parents in both countries use were made between Finland and the United States.

The interviewed participants were four families raising children with Autism Spectrum Disorders (ASD) diagnoses. Two families were living in Finland and two families in the United States. The focus group was selected from high school age adolescence to focus on the continuity of attending educational setting. Narrative research analysis was conducted. It was chosen to find out personal, in-depth experiences of the families. For example, to possibly find out what are the benefits of ongoing open-communication in autistic adolescence development or to find out stressors that impact directly families of children with ASD diagnoses.

Naturally, collected practical study results reflect the limited number of participants. But according to this study, parents of children with ASD diagnoses in Finland felt that they needed better communication methods, such as face to face meetings or phone calls from school personnel at school. These methods would support them with raising their child with autism. Compared to Finland communication in the U.S. was more consistent and considered critical and as a key factor.

The mostly used communication method to approach educators in both countries was by following up with an email. Majority of the parents were also comfortable being in contact with educators by telephone correspondence. School field trips were common for parents to join in and a useful way of establishing good relationships only in U.S.

Parents also experienced difficulties and impolite attitude at school. The most importantly the lack of communication concerning issues which increased the workload and stress of the families with children with ASD.

Analysis showed that in Finland parents are not always the ones that can make active decisions about the communication. It is not too commonly offered option for them to choose the role they would like to play within school environment. The notifying of family needs and ways of effective communication are affected by the school staff's interests, abilities and availabilities. Yet, the child's disability and the complexities associated with it will affect parents' ability to communicate with professionals.

In Finland the parents are quite little involved in their children's school programs. Some parents find it challenging to participate in their children's education. Schools might not know how to reach out to parents to get them involved. Parents identified several barriers affecting their ability to engage effectively with the school staff.

In comparison to Finland, the study found that in United States, open communication is more consisted and considered a key factor for successful partnerships between school and families. Whether these observations have some deeper and conventional cultural or behavioral roots, when comparing communication in Finland to US, was not under scrutiny. Still, that might be a very interesting topic for further studies to learn if the Finnish parents discuss differently than the American parents about the same challenges in communication.

The research can be used on designing of communication pathways within special education at schools, concerning the parents with adolescents with ASD, to make their needs to be met more appropriately. Effective communication as the key factor that can significantly improve the school experience for a child with ASD and parent's

communication can improve student achievement. To make sure parents and professionals can help the child with ASD, they need to co-operate.

It would be wise for parents to share the information with school staff so that they could make decisions together about the child's education. As much as parents have a very important role to play in the lives of their children, their input to their child's educator is even more vital and therefore parent's involvement plays a significant role on child's success. By being an active parent, attending the parent-teacher meetings and for example Open House Nights and truly learn about their child's program at school would make an enormous difference in their child's future. Educators and parents should decide how to communicate right at the beginning and keep a positive and helpful outlook that will make for an easier school year for children with ASD diagnoses. The lines of communication should always stay open between home and school so that parents could ask for and offer suggestions and educators fulfil their requests.

The most significant thing is to understand that whatever the diagnoses are, children with ASD can learn and function productively in society. They can show positive gains with appropriate treatment and education in place. This is all possible when everyone who works with a child with ASD is on the same page. Without the right support the child may never realize his full potential and that is why communication becomes essential. While children with ASD have similar problems, it is important to keep in mind that no two children are exactly alike: if you know one child with autism, you really know only one child with autism.

I enjoyed doing research on ongoing open communication between home and school with families whose adolescence are with ASD diagnoses, as I'm myself educator, parent with ASD child, and because I have lived in both targeted counties that made this research journey very interesting.

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Finnish parent Tanja, 46, with a 19 years old son with ASD. Interviewed in Helsinki, Finland in March-April 2015.

American parent Laura, 45, with a 20 years old son with ASD. Interviewed in Modesto U.S. in June-July 2014.

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## APPENDIX

### Abbreviations

<u>ABA</u>	<u>Applied Behavior Analysis</u>
<u>APA</u>	<u>American Psychiatric Association</u>
<u>AS</u>	<u>Asperger Syndrome</u>
<u>ASD</u>	<u>Autism Spectrum Disorder</u>
<u>BIP</u>	<u>Behavior Intervention Plan</u>
<u>BSP</u>	<u>Behavior Support Plan</u>
<u>CDC</u>	<u>US center of Disease Control and Prevention</u>
<u>DSM</u>	<u>Diagnostic and Statistical Manual of Mental Disorders</u>
<u>ESSA</u>	<u>Every Student Succeeds Act</u>
<u>FAPE</u>	<u>Free Appropriate Public Education</u>
<u>FBA</u>	<u>Functional Behavioral Assessment</u>
<u>IDEA</u>	<u>Individuals with Disabilities Education Act</u>
<u>IEP</u>	<u>Individual Education Plan</u>
<u>HOJKS</u>	<u>Henkilökohtaisen opetuksen järjestämistä koskeva suunnitelma</u>
<u>NCEE</u>	<u>National Centre on Education and the Economy</u>
<u>NCLB</u>	<u>No Child Left Behind (Policy)</u>
<u>OECD</u>	<u>The Organization for Economic Co-Operation and Development</u>
<u>PDD-NOS</u>	<u>Pervasive Developmental Disorder Not Otherwise Specified</u>
<u>PISA</u>	<u>Program for International Student Assessment</u>
<u>PTA</u>	<u>Parent-Teacher Association</u>