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ΜΕΤΑΠΤΥΧΙΑΚΗ ΔΙΠΛΩΜΑΤΙΚΗ ΕΡΓΑΣΙΑ

**Πρώιμη παρέμβαση στη διαταραχή αυτιστικού φάσματος. Ορισμός, σημαντικότητα, διάγνωση, ο ρόλος του εκπαιδευτικού. Η περίπτωση του σουηδικού νηπιαγωγείου: μια συστηματική βιβλιογραφική ανασκόπηση.**

POST GRADUATE THESIS

**Early intervention in autistic spectrum disorder. Definition, importance, diagnosis, the teacher's role. The case of the Swedish preschool: a systematic literature review.**

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## Δήλωση συγγραφέα μεταπτυχιακής εργασίας

Η κάτωθι υπογεγραμμένη Γουσοπούλου Βάγια Ευαγγελία του Νικολάου, με αριθμό μητρώου 19017, φοιτήτρια του Διδρυματικού Προγράμματος Μεταπτυχιακών Σπουδών Παιδαγωγική μέσω Καινοτόμων Τεχνολογιών και Βιοϊατρικών Προσεγγίσεων των Τμημάτων Βιοϊατρικών Επιστημών/ Τμήμα Αγωγής και Φροντίδας στην Πρώιμη Παιδική Ηλικία/Παιδαγωγική τμήμα των Σχολών Επιστημών Υγείας και Πρόνοιας/Σχολή Διοικητικών, Οικονομικών και Κοινωνικών Επιστημών του Πανεπιστημίου Δυτικής Αττικής και της Ανώτατης Σχολής Παιδαγωγικής και Τεχνολογικής Εκπαίδευσης, δηλώνω ότι:

«Είμαι συγγραφέας αυτής της μεταπτυχιακής εργασίας και ότι κάθε βοήθεια την οποία είχα για την προετοιμασία της, είναι πλήρως αναγνωρισμένη και αναφέρεται στην εργασία. Επίσης, οι όποιες πηγές από τις οποίες έκανα χρήση δεδομένων, ιδεών ή λέξεων, είτε ακριβώς είτε παραφρασμένες, αναφέρονται στο σύνολό τους, με πλήρη αναφορά στους συγγραφείς, τον εκδοτικό οίκο ή το περιοδικό, συμπεριλαμβανομένων και των πηγών που ενδεχομένως χρησιμοποιήθηκαν από το διαδίκτυο. Επίσης, βεβαιώνω ότι αυτή η εργασία έχει συγγραφεί από μένα αποκλειστικά και αποτελεί προϊόν πνευματικής ιδιοκτησίας τόσο δικής μου, όσο και του Ιδρύματος. Παράβαση της ανωτέρω ακαδημαϊκής μου ευθύνης αποτελεί ουσιώδη λόγο για την ανάκληση του πτυχίου μου».

Γουσοπούλου Βάγια Ευαγγελία



## Ευχαριστίες

Η διπλωματική εργασία πραγματοποιήθηκε στο πλαίσιο του διδρυματικού μεταπτυχιακού προγράμματος σπουδών «Παιδαγωγική μέσω καινοτόμων τεχνολογιών και βιοϊατρικών προσεγγίσεων» του Πανεπιστημίου Δυτικής Αττικής και της Ανώτατης Σχολής Παιδαγωγικής και Τεχνολογικής Εκπαίδευσης.

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## Περίληψη

Η ποιότητα της πρώιμης παρέμβασης που παρέχεται σε παιδιά προσχολικής ηλικίας με διαταραχή του φάσματος του αυτισμού (ΔΑΦ) είναι ιδιαίτερα σημαντική. Ωστόσο, πολύ περιορισμένη έρευνα έχει ασχοληθεί με το πώς διεξάγεται στην πραγματικότητα η διαδικασία παροχής πρώιμης εντατικής συμπεριφορικής παρέμβασης (EIBI) στα σουηδικά νηπιαγωγεία και ποια είναι τα αποτελέσματα αυτής. Ο σκοπός αυτής της συστηματικής βιβλιογραφικής αναφοράς συνίσταται στη διερεύνηση της διαδικασίας της πρώιμης παρέμβασης στα παιδιά με ΔΑΦ καθώς και τις απόψεις, στάσεις και γνώσεις των εκπαιδευτικών προσχολικής εκπαίδευσης στα σουηδικά νηπιαγωγεία όσον αφορά την ένταξη των παιδιών με ΔΑΦ στην τάξη αλλά και της σημαντικότητας της πρώιμης παρέμβασης. Μεθοδολογικό εργαλείο της έρευνας αποτέλεσε μια συστηματική βιβλιογραφική ανασκόπηση άρθρων και ερευνών (N=8) που αφορούν στο Σουηδικό πληθυσμό τα έτη 2012-2021 με επίκεντρο την παροχή πρώιμης εντατικής παρέμβασης στα παιδιά πρώιμης παιδικής ηλικίας ΔΑΦ στα νηπιαγωγεία της Σουηδίας. Η συλλογή των δεδομένων ολοκληρώθηκε μέσα από τις βάσεις δεδομένων Psych Info, Gothenburgs University Library, CINAHL και Science Direct. Η διαδικασία διαλογής ακολούθησε το πρωτόκολλο PRISMA για συστηματικές ανασκοπήσεις. Μέσω της συλλογής αυτών των δεδομένων προσπαθήσαμε να εξετάσουμε ζητήματα που αφορούσαν την οριοθέτηση των όρων διαταραχή αυτιστικού φάσματος, πρώιμη εντατική παρέμβαση, το ρόλο του εκπαιδευτικού καθώς και τη σημαντικότητα συνεργασίας μεταξύ των επαγγελματιών διαφόρων ειδικοτήτων που εμπλέκονται στη διαδικασία της πρώιμης παρέμβασης. Μετά από εξέταση της βάσης και της υποδομής του σουηδικού συστήματος υποστήριξης παιδιών νηπιακής ηλικίας με αυτισμό με τη χρήση πρώιμης εντατικής παρέμβασης και του συστήματος προσχολικής εκπαίδευσης, παρατηρήθηκαν ορισμένοι περιορισμοί και ελλείψεις στους τομείς των δια-οργανωτικών συνεργασιών, στη γνώση των εκπαιδευτικών για την πρώιμη εντατική συμπεριφορική παρέμβαση και την εμπιστοσύνη σε αυτήν καθώς και στον ρόλο του εκπαιδευτικού παράλληλης στήριξης στο προσχολικό περιβάλλον. Συνολικά, τα αποτελέσματα προσθέτουν στην υπάρχουσα έρευνα και εμπλουτίζουν την κατανόηση του τρόπου με τον οποίο η πρώιμη εντατική συμπεριφορική παρέμβαση θα λειτουργούσε με επιτυχία στο σουηδικό σύστημα και παρέχουν κατευθύνσεις για μελλοντικές συστηματικές βελτιώσεις.



Λέξεις κλειδιά: Διαταραχή αυτιστικού φάσματος, πρώιμη εντατική παρέμβαση, διάγνωση, προσχολική ηλικία, ρόλος νηπιαγωγού

## Abstract

The quality of the early intervention provided in preschool children with autism spectrum disorder (ASD) is a subject of great interest. However, very limited research has addressed how the process of providing early intensive behavioral intervention (EIBI) is used in preschools and what are the outcomes of it. The purpose of this systematic literature review is to investigate the process of early intervention and its importance for children with ASD as well as the views, attitudes and knowledge of preschool teachers in Swedish preschools regarding the inclusion of children with ASD in the classroom. The current systematic literature review, consists of (N=8) articles that apply to the Swedish population in the years 2012-2021 and focus on the implementation of early intensive care to early childhood children with autism spectrum disorder in Sweden. The data collection was completed through the databases Psych Info, Gothenburgs University Library, CINAHL and Science Direct databases. The screening process followed the PRISMA protocol for systematic reviews. By collecting this data, issues related to the demarcation of the terms autism spectrum disorder, early intensive intervention, the role of the teacher as well as the importance of cooperation between professionals of different specialties involved in the early intervention process are addressed. After looking into the groundwork and infrastructure of the Swedish support system with the use of Early Intensive Behavioral Intervention and the preschool education system, certain limitations and deficiencies were noticed in the areas of inter-organizational collaborations, the teachers' knowledge of Early Intensive Behavioral Intervention and allegiance towards it as well as on the role of the paraprofessional in the preschool environment. Thus, the results add to the existing research and enrich the understanding of how an EIBI would successfully work within the Swedish system and provide directions for future systematic improvements.

Keywords: Autistic spectrum disorder, early intervention, EIBI, diagnosis, preschool age, teacher's role

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## Prologue

This dissertation with title “Early intervention in autistic spectrum disorder. Definition, importance, diagnosis, the teacher’s role. The case of the Swedish preschool.” was completed at the University of West Attica in Athens, Greece. It took place in the framework of the Inter-Institutional Post Graduate Program “Pedagogy through innovative Technologies and Biomedical approaches” of the Department of Biomedical Sciences of the Faculty of health and caring professions of the University of West Attica in collaboration with the department of Pedagogy of ASPAITE.

Autism is one of the most serious, complex and chronic disorders that affects the development of the child and its incidence increases rapidly. The society, the educational process, the parents and in general every system is called to respond to this change and to adjust its provision of services based on this increase. Its treatment has been a challenge and object of scientific interest for years. Efforts to address the disorder have led to different early intervention approaches, some of which promise to significantly improve the quality of life of the autistic person. It is generally accepted that the earlier treatment is started and the more intensive the intervention, the better the results.

Generally, Sweden embraces inclusion by agreeing to support the inclusion principles for children with special needs as stated in the Salamanga statement (UNESCO, 1994) and in the Conventions of the Rights of Persons with Disabilities (United Nations, 2006). Children with autism join the regular preschool classrooms and have access to support by paraprofessionals that work directly with them in the preschool environment plus habilitation center staff that are in contact with the paraprofessionals and the child’s family and are foremost responsible for the early intervention provided. Nevertheless, the quality of early intervention provided within the Swedish preschools and the ways that the Swedish system supports children with an ASD raise doubts for many different reasons. Barriers in the Swedish university preschool education, support system and in the inter-organizational collaborations affect the quality of the early intervention provided. Those factors have been acknowledged by researchers the past decade and have awakened my interest as well. As a preschool teacher with an expertise in special needs education, I have worked in Sweden in regular preschool classrooms with children diagnosed with ASD. While gaining more experience of how the system on supporting preschool children with an ASD works in Sweden, I started realizing all the gaps and barriers and got curious to learn more. This is the reason why I chose that as a focus point of my masters thesis. Through my research, some of my conceptions and hypothesis got approved, while I got challenged and stimulated more by gaining and in depth understanding of what predetermines the services provided to children with an ASD in the Swedish society. The most important lesson I learned is that education, cooperation and consistency is key to success in working with children with autism.

This paper is a study on the definition, characteristics and diagnostic criteria of the autistic spectrum disorder (ASD) as well as the definition and the practice of Early Intervention (EIBI) and a try to record how inclusive is the special education in the Swedish preschools through the eyes and knowledge and views of experts on those subjects. ASD's historical background is presented as well as its current definition together with the legal framework of EI in Sweden along with its definition and principles. All the information given is backed up by research data and the existing literature.

## **Chapter A. Theoretical background**

### **1. Introduction**

Autism is widely known and is commonly believed that it always existed. Frith, among others, showed the presence of people with typical autistic characteristics and features in folk tales. Autism is neither a physical or intellectual disability but rather a biologically based, complex neurodevelopment disorder with a strong genetic component that affects the social and communicative development and it is characterized by persistent challenges on those areas. According to Happe, (2006) we might be witnessing an autism epidemic as about 0,6% of the population is thought to have ASD.

Autism is mentioned as a spectrum due to the reason that not two people are affected by it the same way. The autistic spectrum includes subgroups of developmental disorders such as the Aspergers disorder, the pervasive developmental disorder not otherwise specified and childhood disintegrative disorder under the new DSM-5 manual.

Autism can be found worldwide with different prevalence in low-, middle-, and high-income families while more data is still getting collected. Studies that examine the epidemiology of autism nowadays have shown that the pervasiveness estimates of autism spectrum disorders was 62/10000. The earlier epidemiological surveys occurred as early as 1960s and since then a great amount of data has become available indicating a high prevalence of the condition. (Elsabbagh et al., 2012) According to Baird et al., (2006), the prevalence of ASD is greater than ever with a higher than ever increasing number of cases around the world. Many different reasons such as better ascertainment, broadened diagnostic criteria and the increased incidence may have contributed to a more clear recognition of ASD cases, who constitute 1% of the child population. The World Health

Organization states that one in 160 children has ASD, or even higher than that. The male-to-female ratio in ASD according to a recent study that analyzed 54 different studies is stated to be closer to 3:1 rather than 4:1 that was commonly assumed before. (Loomes et al., 2017)

As a consequence to the increasing number of ASD cases, more children participate in general education. (ASD Centers for Disease Control and Prevention 2007). Many professionals such as teachers, special education teachers, pediatricians, psychologists, neurologists, speech therapists, physiotherapists and more may be found in different environments working with children with ASD.

### **1.1. Pervasive Developmental Disorders**

Pervasive Developmental Disorders is a term that covers the whole autistic spectrum. In PDD autism is included as well as more high-functioning disorders such as Asperger's syndrome and other forms of autism. There are two official classification systems for PDDs. The first one is that of the American Psychiatric Association (DSM-V) and that of the World Health Organization (ICD-10).

Notas (2005) claims that this group of pervasive developmental disorders is characterized by odd social transactions and ways of communication, as well as by a limited, repetitive interests and activities that are stereotypical. These qualitative abnormalities may vary in severity and are a diffuse feature of the individual's functionality, under any circumstances.

In the DSM-IV, five pervasive developmental disorders are included: Autistic Disorder, Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). In May 2013, a new revised version of the DSM was published (DSM-V) which included significant adjustments to the already existing diagnostic criteria.

These changes are as follows:

The term Autism Spectrum Disorder (ASD) has replaced the the general term Pervasive Developmental Disorders (PDD). Other than that, the diagnostic subcategories Autism, Asperger Syndrome, Childhood Disorder and Pervasive Developmental Disorder (not otherwise specified) have been eliminated meaning that all of them have been combined

into a single category of Autism Spectrum Disorder. The group of these disorders has common clinical features, neuropsychological deficits and genetic origin and is now described as Autism Spectrum Disorders.

Although the changes were made to address the problems of the DSM-IV, they were discussed extensively before and after their publication, while at the same time there is intense concern about what changes their implementation might bring. The aim of this change was to more accurately characterize children with social communication and interaction deficits, as well as restrictive and repetitive behaviors and interests. (Kupfer, Kuhl and Regier, 2013) People who have already been diagnosed with Asperger's Syndrome or an other PDD are worried that they will lose their diagnostic identity. In practice, it seems that those who already have a diagnosis, it will remain as it is and they will continue receiving treatment and educational services. It also seems that experts and professionals will continue to use the existing terms (Asperger, etc.) even unofficially. Other concerns are related to the possibility of differentiation in diagnostic performance. Preliminary studies show that with the new diagnostic criteria there are no significant differences, but research on the subject continues.

## **2. What is autism?**

Giving autism a definition may seem hard as there are many different sources that present it with some slight differences. There are professionals and organizations that throughout research have given definitions. They all have something in common, autism is a neurodevelopment disorder, affects the human development in many different areas and is very heterogenous. It is characterized by impairments in social interaction and communication as well as repetitive patterns of behaviors and restricted interests. It can be detected during childhood through behavioral evaluations by specialists and stays lifelong, although symptoms may improve overtime. Until now, there is no known cause that could explain why ASD occurs. Research has shown that genetic factors may affect the most the occurrence of autism. Environmental risk factors may also be an etiology that may be involved with the occurrence of ASD. (Lichtenstein, Carlström, Råstam, Gillberg, & Anckarsäter, 2010; Sandin et al., 2014).



For the definition of autism, medical science has defined criteria (World Health Organization, WHO), ICD-10, International Classification of Diseases, 10th edition, WHO 1987. DSM-V Handbook of Diagnostics and Statistics, 5th edition , 2013) Autism is a spectrum of disorders, with a common basis, but with different intensity in the clinical manifestations and the functionality of the patient. The 2 official classification systems, DSM-V and ICD-10 almost identically describe the disorder in a developmental sense and they both now include a number of other related disorders for which Autism is the original disorder.

Autism is the result of a neurological disorder that affects the functioning of the brain and manifests itself in an informal form of communication, social skills and abilities to play and respond to incoming sensory information. According to Polychronopoulou (2012) the definition that is commonly accepted is the one that is suggested from the DSM-IV. Autism's commonly accepted definition that describes it the best includes data from previous statements.

Polychronopoulou (2012) states that autism is placed in the spectrum of complex neurodevelopmental disorders which are mainly biological in nature and are the result of multiple genetic and neuropathological mechanisms. In addition, it is considered a chronic and diffuse developmental spectrum disorder. It is called "chronic" because it is a lifelong disorder that does not go away after some point in life, "diffuse" because it affects multiple developmental areas and "developmental" since the disorder occurs during the developmental period. Moreover we use the word "spectrum" because the clinical picture of autism is heterogeneous and the set of core features covers a spectrum of behaviors, as it ranges in a continuous line from the mildest forms (children with normal intelligence and few autistic elements) to the more severe forms (children with severe mental retardation and multiple autistic elements). As (Happé, 2001) mentioned, "the manifestation of autism varies greatly with age and ability, from the silent, aloof, and developmentally delayed child, to the verbose, over-friendly and intelligent adult."

"Autism spectrum disorder (ASD) refers to a range of conditions characterized by some degree of impaired social behavior, communication and language, and a narrow range of interests and activities that are both unique to the individual and carried out repetitively. ASDs begin in childhood and tend to persist into adolescence and adulthood. In most cases the conditions are apparent during the first 5 years of life. Individuals with ASD

often present other co-occurring conditions, including epilepsy, depression, anxiety and attention deficit hyperactivity disorder (ADHD). The level of intellectual functioning in individuals with ASDs is extremely variable, extending from profound impairment to superior levels." - *World Health Organization*

"Autism spectrum disorder (ASD) refers to a group of complex neurodevelopment disorders characterized by repetitive and characteristic patterns of behavior and difficulties with social communication and interaction. The symptoms are present from early childhood and affect daily functioning." - *National Institute of Neurological Disorders and Stroke*

The term Autistic Spectrum Disorder or "autism" are derived from the Greek word "eautos" that means "self". It was previously used to describe schizophrenic patients, according to Ulla Frith. Kanner in his publication *Autistic Disturbances of Effective Contact*, described some of his child patients "like in a shell", "acting as if people weren't there", and "perfectly oblivious to everything about him". Those descriptions seem to perfectly picture the self-absorption that is associated with the ASD. (Sanders, 2009) In other words, the Autistic Spectrum Disorder of "autism" is generally defined by an apparent disconnect from the social world outside themselves.

People with autism have identified it as follows:

"Autism is not the shell of the individual. It is pervasive in every aspect of the individual. It's a way of being. " (Jim Sinclair, person with autism).

"Autism is a distraction from the external reality that accompanied by an intense inner life ". (Petit Robert, person with autism).

"Autism is a developmental disorder. A defect in the systems that process sensory information "(Temple Grandin, person with autism).

"Autism is not a label - recognizing the difficulties that a label can cause - but a label. That's the decent thing to do, and it should end there "(Exley, person with autism) (Gonella, 2006).

## **2.1. Etiology of the disorder**

ASD is very complex and heterogeneous disorder. Currently, there is no known cause of autism but it appears to be multiple etiologies. According to research the genetic factor plays an important role in the development of autism, meaning that autism can be a

hereditary disorder. Environmental factors have a more subtle effect in the development of autism. Genetic, perinatal or environmental factors may act either individually or in combination. Heredity also works cumulatively, but the individual risk of developing ASD and to what extent it is caused by genetic or environmental factors remains unclear. These factors probably interact in the majority of cases and so the assessment of individuals and the contribution of genetic factors is further complicated (Fett-Conte, Bossolani-Martins, & Rosan, 2015).

Genetic factors undoubtedly play a dominant causal role in the onset of autism. The change in the number of copies of DNA, which is a form of structural change that manifests itself as deletion or duplication in the genome, has gained prominence at the stage of discovering the causes of autism (Fett-Conte, Bossolani-Martins, & Rosan, 2015). However, genetic factors alone cannot fully explain all cases of the wider autistic phenotype (Schaafsma & Pfaff, 2014). Other researchers support the multifactorial nature of autism (Glasson, Bower, & Petterson, 2004; Lampi et al., 2012) by highlighting the role of environmental factors, suggesting that specific environmental factors may act as risk factors that trigger autism. Environmental risk factors include conditions such as exposure to toxins, maternal eating habits during pregnancy until premature birth, and parental age at conception. Due to the fact that the prevalence in siblings is close to 20%, more research studies those cases. Sibling and twin studies add to the understanding of whether there is a genetic and environmental risk factor involved in the etiology of ASD.

Thus, anything that affects the DNA replication system can interfere with mental health, something that creates many possibilities, meaning that pretty much anything can cause autism and there is a risk of over or underestimating certain factors. Gene expression, in collaboration with vulnerable immune systems and environmental stressors, need to be organized using an interdisciplinary approach in order to explain what really happens in the normal evolution of DNA replication within the first three years of life (Fett-Conte, Bossolani-Martins, & Rosan, 2015).

In summary, ASD is a very heterogeneous disorder and that corresponds to the complexity of the factors that predispose to its appearance. A variety of genetic factors are complemented by a variety of environmental factors. From the above information it becomes clear that genetic and environmental impacts can not be considered as independent

factors. Therefore, the importance of their combined study increases. Science focuses mostly on the most common risk factors with a goal to support the individuals with ASD and their families in order to improve the quality of life. (Fett-Conte, Bossolani-Martins, & Rosan, 2015).

## **2.2. Historical background**

What is very interesting about autism is that even though the first information about it came after the 1900s, we knew it existed before that. Autism was pictured in old story books, myths and real life documented cases of “abnormal” people that with our knowledge now looks like picture in the Autistic Disorder Spectrum. Like now, people were always trying to understand it, define it and figure it out what is it that makes it so special.

Ula Frith (1994) mentions fascinating examples of legends and historical people, who may have had some autistic characteristics: the collection *The Little Flowers of St. Francis*, on the 13th century contains stories about the first companions of the Saint. Nones story resembles the story of Brother Juniper, through which one side of autism emerges, that is, the completely naive and guileless perception of things.

The case of a five-year-old boy admitted to the Mental Illness Asylum in London (1799) is described by the asylum pharmacist as a strange child who never played with other children, but alone, lining up soldiers.

In 1828, a strange young man appeared in Nuremberg who, walking, kept saying, "I want to be a horseman like my father." Kaspar Hauser, 16, died at the age of five. His story has frequently been cited for relevance to understanding historical background of autism. Many years later, Genie, another “weird” child was found with many similar characteristics as Kaspar.

The distant, eccentric and quirky detectives of detective novels (Sherlock Holmes, Hercule Poirot, Colonel Marple ...) remind us people with “autistic intelligence” according to H. Asperger. What about Albert Einstein and Isaak Newton? Two extremely intelligent men that many experts in autism claimed that they had some autistic features and some symptoms of the Aspergers disorder. Of course, it is impossible to make a diagnosis for people that are not alive, everything is just a theory.

It is impressive if we look at how many myths, theories and stories are created around autism but those myths can only talk about specific areas of autism and not about every aspect of it. All those stories are fascinating to read but they tell half the truth for such a complicated concept. What will help us is the scientific research, which is necessary, necessary and must go further, in depth, to give us information, knowledge and from the existing data, some to be rejected and others to be recognized. The processing of new data will help to cover the autism phenomenon.

The discovery of autism came on the 20th century where people with behavioral difficulties would become more and more visible and that was a call for new professions to be discovered and developed such as educators, psychiatrists, speech therapists and child development specialists. Eugen Bleuler, a Swiss psychologist, was the first to introduce the term "autism" as a symptom of schizophrenia. Bleuler considered autism as an escape from self, the Greek word "autos", an escape from schizophrenia into a state of self-absorption. That discovery of course brought attention and by the 1930 many different professionals were caught up trying to define the normal development and the abnormal development and also what causes somebody to deviate from it. (Barnett, 2016) Until the 1950s many psychologists, psychoanalysts and psychiatrists would use the word "autism" in the UK.

Autism counts about 70 years of scientific life if we count as a milestone of its proven recognition, the presentation of the term from Kanner in 1943. Kanner was the first one that reported a small case series, a group of children who showed as a core characteristic their tend to isolate themselves and extreme and obsessive tendency of repetitive behavior such as echolalia. Those's children tendencies were very similar to childhood schizophrenia but as it seemed different from recorded incidents of schizophrenia. First and foremost, Kanner's patients exhibited extreme aloneness from birth while the schizophrenia patients had a so called normal development prior to the onset of their disorders. The term "autism" was introduced in child psychiatry even though there was still a few explanations and knowledge on its biological causes. Kanner framed it as a condition characterized of the absence of "affective contact" and the lack of social reciprocity. (Sanders, 2009) After that, autism completely reformulated as a new child development category.

The next big step was made during the 1960s and 1970s from Beate Hermelin and Neil O' Connor, who separated autism from schizophrenia and mental illness. Since then,

autism is established firmly in the discipline of mental handicap. More epidemiological work was made later on from Wing and Judith Gould in the UK. Autism was then marked as a syndrome with its three cooccurring impairments in socialization, communication and flexible behavior. They also introduced the term "spectrum" and unlike Kanner's notes, not only children who were silent and withdrawn could have autism. Children being unusually passive, with an odd social behavior while communicating pedantically with over-formal speech is now a sign that these children could be on the "autistic spectrum". Wing raised awareness that the manifestation of autism varies with age and ability.

Child psychiatrist at the UK Maudsley Hospital, Michael Rutter conducted the first ever genetic study on autism at 1972. His findings were the exact opposite of what autism had meant up until that time. Rutter claimed that "the autistic child has a deficiency of fantasy rather than an excess" (Rutter, 1972: 327) That scientific finding gave a different meaning to the word autism. (Evans, 2013)

When it comes to the development of the diagnostic criteria, Kanner's findings through his descriptions of the 11 children on his article have been arguably influential. Only nine years after Kanners article, the first edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) was published (APA 1952) and the second edition got published 6 years later. In both of those editions, autism was not categorized as a disorder but as schizophrenia as most of the diagnostic criteria for autism was present as diagnostic criteria for schizophrenic disorder. DSM-II describes childhood type schizophrenia as a condition manifested by "autistic, atypical and withdrawn behavior". (p. 35, 1968)

Since then there has been a phenomenal increase in diagnoses of autism and that attracted many different scientists and brought light into the research area. After the publication of the DSM-II many changes in the diagnostic methods were made, up until the 1980s and autism came to be associated with "profound mental retardation and other developmental or physical disorders" (Wing, 2002) In 1976, Lorna Wing referred to the "Triad of Disorders" and the difficulties faced by people with autism in the areas of socializing communication and imagination.

The first inclusion of autism as a disorder on its own was in the DSM - III in 1980 and it was under the name Infantile Autism, which later changed to Autism in the revised DSM-III in 1987. The definitive abandonment of the term psychosis and the introduction of

the term developmental disorders, which is accepted today, took place in the 10th edition of the ICD (1992), and in the third (1980), the third revision (1987) and the fourth revision (1994) of the DSM. In May 2013, the fifth revised version of the DSM (DSM-V) was released.

Over time a substantial body of data was collected that to that point and in our understanding of the disorder leads us to its definition of the medical basis.

## **2.2. Diagnosis**

The grid of three major deficiencies, known as the Wing Triad, is the basis for diagnosing autism. Diagnosing autism is not an easy process, because it is not performed - to date - by laboratory and blood tests. Autism is likely to coexist with other clinical condition which makes experienced professionals find it difficult to diagnose. In different cases and situations, the views of experts differ regarding the diagnosis of children and adults. Experts observe, follow psychological procedures and compile a complete history before making a diagnosis. A very important clinical goal is for specialists to figure out whether or not the child has an autism spectrum disorder. When that question gets answered they move on into assessing their abilities.

The best tools for assessing autism is observation and discussion. For autism to be evaluated and diagnosed we need to look at the person as a whole. The complex nature of the difficulties and disorders in ASD may require involvement in the diagnosis and treatment of different specialists working in different services. The needs of the child and the family are best addressed when specialists recognize the range and knowledge of the skills required for early diagnosis. The evaluation can be formal and informal. By formal we mean that which is done by teachers, psychologists, social workers. The informal is superior to the formal. It gives us emerging skills, strengths, weaknesses, interests, styles and ways of learning.

Developmental tests, medical examinations and measurements of adaptive behavior are used together with diagnostic instruments in order to diagnose ASD in children. The most known diagnostic instruments are the Autism Diagnostic Interview- Revised (Rutter, Le Couteur, & Lord, 2003) together with the Autism Diagnostic Observation Schedule (Lord, Rutter, DiLavore, & Risi, 1999). In an effort to diagnose autism as early as possible the Modified Checklist for Autism in Toddlers (M-CHAT) is used in primary healthcare.

Whenever it's possible, an examination and assessment by a speech and language pathologist and an occupational therapist is preferred .

The diagnosis for a child with autism is very important and can start as early as the 3rd month of the baby's life, where the child must first be examined medically to determine if the behavior he exhibits is influenced by a congenital trait. It is necessary to examine the child's attitudes in many different contexts in order to form complete and accurate conclusions. Also, his reactions to the stimuli that accepts, how it perceives information but also what influences it receives from its environment (Gould, 2007).

An early diagnosis can be very beneficial for the child itself, the family around it as well as the educational framework that the child exists in. Early diagnosis leads to early intervention. Intensive early intervention in the appropriate context, results in young children with autism, improving their performance in speech up to their developmental progress and cognitive abilities. Diagnosis aims to reduce family stress and provide family support and appropriate medical and educational care to the child. The purpose of it is to help understand the problem, provide guidance to those directly involved with the child in order to have results and to suggest ways for appropriate and effective future interventions.

According to the Swedish Association for Autism & Aspergers syndrome (2020) children with autism and intellectual disabilities today are often diagnosed at an early pre-school age. For children with autism and aptitude within the normal range, it is more common to be diagnosed between the ages of 8 and 11, even if thoughts have been raised earlier. Girls are still diagnosed later than boys, even though the parents contacted child and adolescent psychiatry at the same age as boys. Some people with autism are not diagnosed until adulthood, sometimes after many years of diffuse difficulties and personal suffering. When investigating both children and adults, a thorough review is made of the person's development from early childhood. An assessment is made of the current situation and of the person's strengths and weaknesses. Together with a number of tests and sometimes even medical examinations, the decision on autism diagnosis is also the basis.

Undoubtedly, a correct and early diagnosis is crucial when it comes to children. Otherwise, children with ASD's can be sentenced to a life of underestimation, inadequate care and without addressing their special needs. The purpose of the diagnosis is: To help us understand problems, to provide guidance to teachers, parents and others who concern



the child's condition and its consequences and to suggest ways of effective handling and educational strategies (Notas, 2005)

Early diagnosis, early adapted interventions and good information for all concerned are needed to provide the best possible conditions. Pedagogy, environment and support need to be adapted based on the individual conditions. Aids for communication and time perception may be needed. With the help of apps, pictures or written text, get support for functioning independent communication based on your own level is important for a good quality of life. Some people with autism will in adulthood have working strategies and an independent life without support measures. Others will have some need for support and some more will have an extensive need for support throughout life. With the right support and the understanding and acceptance of those around you, a need for support does not stand in opposition to a good life. (Autism.se, 2020)

### **2.3. Diagnostic criteria**

It is crucial to identify atypical development early in life as it can affect access to early intervention, healthcare and a well rounded support system. (Roll-Pettersen et al., 2016). The quality and quantity of available information varies, something that can lead to different opinions diagnostic disagreements among professionals. That is a product of the diversity of the spectrum and the huge amount of information sources. However, goal is to improve the diagnostic accuracy and that can only be accomplished through a firm establishment of the criteria that lead to a diagnosis. Theoretically, a diagnosis can occur after the first year of life but in practice, diagnose usually happens later in life. In order to achieve this process, the participation of a diagnostic team is required, which consists of pediatric psychiatrists, developmental psychologists, psychologists, speech therapists, occupational therapists and special pedagogues. A thorough evaluation consists of the following steps: taking of the family history, physical examination of the child with the use of a net of weighted scales and use of standardized diagnostic tools.

There are currently two standardized diagnostic systems for establishing a diagnosis. The DSM-V (2013) which is the fifth edition of the Diagnostic and the Statistical Manual of Mental Disorders from the American Psychiatric association and the 10th revision of the International Statistical classification of diseases ICD-10 are two different systems that

have a lot in common and a few differences in the way they conceptualise disorders in the pervasive developmental disorders bundle. (Fatemi & Clayton, 2008)

Due to the disorder itself being very heterogenous and not following a straight line, it may look different in different people. Healthcare providers and professionals use a standard reference tool in order to diagnose autism is the **DSM-V**. There, the diagnostic criteria of autism are stated. According to the DSM-V, autism spectrum disorder is divided into two main categories of symptoms: a) deficits in social communication and social interaction and b) limitation of repetitive behaviors, interests and activities and the diagnosis should be based on the symptoms observed. at the given time or from the history of the individual according to these two areas.

Autism spectrum disorder is divided into three levels of severity in order to better represent the spectrum.

1) Level 1 "Need for support" (Difficulties below),

2) Level 2 "Need for enhanced support" (significant difficulties)

3) Level 3 "need for particularly enhanced support" (serious socialization and flexibility difficulties)

-Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

-Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

-Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

-Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

-Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with

transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).

-Highly restricted, fixated interests that are abnormal in intensity or focus (e.g, strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).

-Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life).

Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

("Autism Diagnosis Criteria: DSM-5 | Autism Speaks", 2020)

According to **ICD-10**, the diagnostic criteria for "Childhood autism (F84.0)" are as follows:

A. Presence of developmental abnormality or delay in at least one of the following areas before the age of 3 years (usually not preceded by a period of clear normal development, but if present, does not extend beyond the age of 3 years):

1. In understanding or expressing language, as used in communication.
2. In the development of selective social contacts and / or mutual interaction.
3. In the functional and / or symbolic game.

B. A total of at least six symptoms from (1), (2), (3) must be present, with at least two from (1) and at least one from each (2) and (3).

(1) Qualitative impairment in mutual social interaction are manifest in at least two of the following areas:

(a) Absence of direct eye contact, facial expressions, postures and gestures to regulate social reaction.

(b) Failure to develop relationships with their peers, including the "sharing" of mutual interests, activities and feelings.

(c) Rarely seek or approach other people for relief and affection in times of stress or sadness and / or lack of comfort and love when others are anxious or sad.

(d) Lack of awareness of other people's joy and / or spontaneous search for other people's participation in their own joy.

(e) Lack of social-emotional response as evidenced by the weakened or deviant response to other people's feelings and / or lack of adjustment of behavior according to the social context, and / or inability to activate social, emotional and communicative behaviors.

(2) Quality impairment in communication are manifest in at least on of the following areas:

(a) Delay or complete lack of spoken language, which is not accompanied by an attempt at compensation through the use of gestures or imitation as an alternative model of communication.

(b) Relative failure to initiate and maintain an alternating dialogue (regardless of the level of language skills available), in which there is no to and in response to communication with the other person.

(c) Stereotypical and repetitive use of language and / or idiosyncratic use of words or phrases.

(d) Irregularities in the intensity, emphasis, speed, rhythm and tonality of speech.

(e) Lack of variety and spontaneous symbolic play or (when it comes to young children) the game of social perception.

(3) Repetitive and stereotyped patterns of behavior, interests and activities are manifest in at least on of the following areas:

(a) Employment surrounded by stereotypes and limited models of interests.

- (b) Special attachment to unusual objects.
- (c) Obviously pathological obsession with certain non-functional routines and rituals.
- (d) Stereotypical and repetitive motor maneuvers, involving "flight" or rotation of the hands or fingers or complex whole-body movements.
- (e) Dealing with parts of objects or the non-functional part of the toy material (such as smell, surface sensation or noise / vibration caused by a toy).
- (f) Stress from subtle, non-functional details in the environment.

C. The clinical picture is not attributed to other pervasive developmental disorders (Asperger syndrome, Rett syndrome, Disorder of Childhood), nor to any specific language development disorder with particular socio-emotional problems, to reactive contact disorder, to mental retardation with partially involved emotional / behavioral disorder, or unusually early onset of schizophrenia. (lancommunity.org, 2017)

The emphasis in diagnosis is no longer on giving a name to the condition, but on identifying the individual's needs and their impact on his or her life (American Psychiatry Association, 2013). The above and the limitations, which vary in severity from person to person, are characteristics of its functionality.

#### **2.4. Clinical features of autism**

Autism is one of the most complex developmental disorders and recent findings show that autism is the product of numerous genetical and neuropathological mechanisms, something that makes the search for biological sings more complicated. According to psychologist Liza Varvogli (2006), the only way to diagnose autism is through careful and detailed monitoring of behavior.

In general, the symptoms of autism can be recognized as behavioral "deficiencies" and "surplaces". Some children show symptoms as early as their first year of life while other don't show until after 3 years old. Some children with ASD even seem to have a normal development until they stop gaining or start losing specific skills they once had. ASD has as core clinical characteristic, impairments in four different areas.

##### **Social interaction**

Initially, children of typical development begin at the age of one to use body language to communicate, ask for something or even to express their dissatisfaction while trying to understand how people communicate with each other using non-verbal communication. In contrast, children with autism at this age do not express themselves by utilizing their face and at the same time do not signal through gestures even if they want to express strong emotions or desires (Wiseman, 2009). Even when they use various gestures then they do it to control someone's behavior and not to communicate with them (Shymko, Bolter & Freeman, 2017).

Moreover, children without autism aged 6 to 12 months seek social interaction with other people as opposed to children with autism where they like to deal more with inanimate objects so this leads to their exclusion from the social environment. At the same time, they do not express their joy even if a person treats the child with autism favorably, engages in individual activities and uses someone's hand when they want to express themselves about something (Wiseman, 2009) At the same time, children with autism are not possessed by the characteristic of empathy and are indifferent to understanding someone's emotional state (Miles, 2011).

### **Communication**

Speech delay is one of the first signs that awakens concerns about whether or not a child has autism. Children aged 1-2 years with autism are indifferent to discovering the characteristics that govern a speech, therefore they are unable to follow the principles that characterize speech in order to e.g. to narrate a series of events in a semantic sequence. Also, while hoarseness characterizes people with autism, infants with this disorder do not repeat the words they hear in their daily lives in order to gradually integrate them into communication with those around them (Paul, 2008).

Children with autism use expressions or words before they even begin to speak in a way that one may not understand what they want to say, while their level of understanding of what one wants to say is very low for their age. This results in them having an incomplete vocabulary based on the repetition of only a few phrases or individual words (Mitchell et.al, 2006).

Another feature that characterizes infants with autism is the fact that they can not express what they want through their gaze. There is no thus synchronizing their gaze

between what they want to acquire and the person who can offer it to them. Therefore, it is possible e.g. to they look intensely at an object without at the same time looking at the person next to them who could give it to them (Travis & Sigman, 2001).

At the same time, children with this disorder are not interested in sharing with other people their own achievements that they are likely to have achieved or something that generally makes them happy, which is directly related to communication as in these conditions speech is cultivated (Landa, 2007).

To conclude, there are some so-called “red flags” in communication skills that might appear in children with an ASD such as: deficits in social communication and joint attention. That means that there may be an absence of response to their name by 12 months of age, default at pointing at objects by 14 months, lack of pretend playing by 18 months, absence of eye contact and need to be alone. ("Signs & Symptoms | Autism Spectrum Disorder (ASD) | NCBDDD | CDC", 2020)

### **Rigid ritualistic behavior and interests**

This type of repetitive behavior does not remain the same throughout the life of an autistic person as e.g. the degree of manifestation, the frequency of manifestation, etc. may be different in adolescence and different in adulthood (Militeri, Bravaccio, Falco, Fico & Palermo, 2002).

Repetitive and stereotyped behaviors are often seen together with a limitation in interests and activities. Behaviors such as flapping hands, fixedly following routines with odd fixations on items and unusual interests are some core clinical features that have the ability to reduce the child’s attention and ability on focusing and learning from their immediate environment. It may involve clinging to specific words or phrases, gestures or even constant engagement with objects, which is common in children with autism as their play is very limited in their creative imagination as it relies on repetitive ways of using it (Cunningham & Schreibman, 2008). The higher cognitive functions of children with autism which are responsible for behavior and emotions begin to be cultivated at the end of the first year with the beginning of the second, but the lack of innovative ideas and for the use of the play becomes apparent during last months of the first year of life (Baranek, Barnett, Adams, Wolcott, Watson & Crais, 2005).

At the same time, at the age of 2.5 years, children with autism may show self-traumatic tendencies which may not be able to stop them, while at the same time children with autism under the age of 1.5 years may exhibit stereotyped movements that they involve their hands such as hitting but also foot movements such as 'walking on the toes' (Trevarthen & Daniel, 2005).

### **Sensory stimuli**

Problems with children with autism that are related to their sensory perception become apparent from the age of 9 to 12 months (Baranek, 2002). Although children with autism show great sensitivity to the information and influences they receive through all their senses, the stimuli they receive through hearing have been given more emphasis because they are associated with language deficits (Baranek, David, Poe, Stone & Watson, 2006).

Sensory stimuli include three characteristics: a) hypersensitivity where the person responds to stimuli faster and more intensely, b) hypersensitivity in which the person seems apathetic to the sensory influences he receives and c) searching for sensory information where the person is looking for stimuli and even those that will have a form of intensity (Miller, Anzalone, Lane, Cermak & Osten, 2014).

As for the senses through the eye, the early signs become apparent as early as the 2nd month of the baby's life as it seems to have an indefinite gaze that does not focus on any stimulus. Also, in the senses that have to do with hearing, the baby already from the 2nd trimester of his life seems to be 'deaf' as he/she does not direct his/her attention to a voice that in fact it may be familiar, while at the same time it may be more attracted to sounds that are not of human origin (Carel, 2000).

The findings of Tomcheck and Dunn (2007), showed that children aged 3-6 years with autism who participated in the study, in contrast to children of typical development of the same age range, like to hear strange sounds or often seem to not hear what someone tells them. At the same time, they react strangely to loud noises. Due to the fact that children with autism suffer from an attachment to repetitive routines, this automatically puts them in a tendency to maintain stability and permanence in food as well, choosing foods with a specific texture and texture each time, and avoiding any other form of food (Suarez, Nelson & Curtis, 2014).



That way there is a great possibility that play skills and interaction with peers will be affected and not thoroughly developed. That can be shown as lack of empathy to other people's feelings, may use speech in an idiosyncratic manner such as echolalia, giving unrelated answers to questions, being uncomfortable with slight routine changes, having obsessive and repetitive interests and movements as well as unusual reactions to the way things sound, smell, taste, look or feel. ("Signs & Symptoms | Autism Spectrum Disorder (ASD) | NCBDDD | CDC", 2020) Others may have fully developed language but difficulties in understanding and interpreting words and meanings. According to Dawson (2008) autism is more of a social motivation disorder as children are less motivated by socially mediated stimuli.

### **3. Demographic factors and prevalence of the disorder**

#### *Age*

According to Mandell (2005), in the USA the average age of diagnosis is 3.1 years old while children who live in rural areas received a diagnosis 0.4 years later than urban children. Children of families who are closer to the poverty level received a diagnosis 0.9 years later than the wealthier families who are way above the poverty levels. Furthermore, children with severe language deficits received a diagnosis an average of 1.2 years earlier than other children. In Europe, ASDEU found that diagnosis is a big problem as the average age first concerns about autism are identified is 25.3 months, while diagnosis doesn't happen until 19 months later. ("Autism Spectrum Disorders in the European Union (ASDEU)", 2018) Recent research on global prevalence of ASD had shown that there has been an increased number of overall cases with a median prevalence of 62/10,000, which in other words means that one out of 160 children has ASD. (Elsabbagh et al. 2012; World Health Organization 2017). According to the World Health Organization (2014), these children and their families are more likely to face social stigma, isolation and discrimination.

While going into adolescence some children may become more socially aware but still have some problems in certain behaviors. Some individuals might improve their overall functioning levels while others might lose some of their skills. Research shows (Fein et al., 2013) that it is possible that a minority of individuals might lose their symptoms overtime

and as adults may not need services since they will be able to blend in with the general population.

#### *Sex*

Recent research findings (Loomes, Hull, & Mandy, 2017) that analyzed 54 different studies with 13,784,284 participants, of whom 53,712 had ASD (43,972 boys and 9,740 girls) showed that the Male-to-Female ratio in ASD is closer to 3:1. One potentially important factor for that ratio is the diagnostic bias. When it comes to girls it looks like they could be not receiving a clinical diagnosis even though they may have the criteria for ASD or they are getting tested later in life, meaning that there might be a diagnostic gender bias that we should be more aware of and that indicates that the condition is harder to spot in girls. Doctors, teachers, parents and others think that the condition primarily affect males and that is another reason why females could be overlooked.

#### *Race/Ethnicity/Nativity*

Studies have found that maternal race is associated with the diagnosis and severity of ASD. (Becerra et al., 2014)

#### *Socioeconomic status*

Research study findings (Durkin et al., 2010) showed that in the past ASD was observed mainly in families of high socioeconomic status. Even though there is an association between ASD and SES indicators such as income, parental education and occupation, the observation that ASD affects mainly high SES families is a bias as it was likely due to barriers of families of lower SES in accessing diagnostic and therapeutic services. In fact, a study conducted in Sweden (Rai et al., 2012), which is a country that provides universal health care as well as access to diagnostic and treatment services found out that lower socioeconomic status was associated with an increased risk of ASD. That is an important finding that rings the bell for the underestimating the burden of ASD in lower SES groups.

Data shows us that there is globally a raise of about 1-3 percent in diagnoses of children with ASD in high income countries. ("Data and Statistics on Autism Spectrum Disorder | CDC", 2021) There are many reasons that have led to an increased prevalence of ASD in recent years. Among others, changes in diagnostic criteria, comorbidity with other diagnosis, practices used in detection and diagnosis, special education policies, availability of services, knowledge and awareness levels regarding ASD have led to an increase in the

incidence and prevalence of the disorder, and that means a parallel increase of children with ASD being educated in mainstream preschools.

### **3.1. Prevalence in Sweden**

Sweden is a multicultural country with a great number of immigrants and refugees. One in five children that live in Sweden have at least one parent born on a different country (Swedish National Board of Health and Welfare, 2013). According to the office of Autism Research coordination [OARC] Sweden is on the 10th place out of 25 countries for publishing ASD research from its research community during 1980-2010. Moreover, the Swedish researchers have been among the first ones that started to research the case of associations between immigration, ethnicity and potential risks for autism spectrum disorders among children of immigrant parents.

According to Barnevik-Olsson (2008) this emphasis on cultural variables is very important for the development of services for culturally diverse children with ASD and their families. The prevalence rate of ASD in Sweden is estimated to be almost 1% (Nygren et al. 2012). Multiple studies examine how ethnic origin is associated with the occurrence of Autism. For instance, according to a recent study conducted in Sweden and more specifically in Stockholm, a rate as high as 2,5% is shown among teens. (Idring et al., 2015) At Stockholm region, the number of preschool aged children that have been diagnosed with autism has doubled during the last five year, according to a recent research. (Kosinou, Edwin, Magnusson & Dalman, 2017) Gothenburg, the second biggest city and a metropolitan area on the west coast of Sweden, has child health care systems that follow up 95-99% of the children from their first years of life. (Arvidsson, Holmberg, Reuter, & Strömbom, 2010) A study by Cederlund et al. (2014) researched 33 different children. Out of them, 6% had a parent born in another city in the EU, 6% had a parent born in an other country of the world, while a 49% of the participants had both parents born in an other country outside Sweden. Such findings raise concerns and questions whether immigration and ethnicity are somehow connected with ASD's, while necessitates from Swedish researchers to report any cultural factors in their empirical research. Furthermore, researchers Cederlund, Miniscalco and Gillberg (2014) noted a high percentage of children with ASD having both parents born outside Sweden (61%).

The Swedish research community do consider ethnicity as a factor that affects the ASD prevalence. (Zaroff & Uhm, 2012). Researchers try to understand more this phenomenon due to the fact that there are underlying associations between ethnic origin, migration status and ASD that are still unclear and need to be further examined. (Idring et al. 2015) so we can get a better understanding of how ethnic and cultural factors are described in ASD research literature.

As a fact based on the epidemiological data, that the number of children who get diagnosed today has risen, due to the fact that children get diagnosed more often and at a younger age.

#### **4. Treatment and outcomes**

Autism spectrum disorder is not a treatable condition but one that can be improved with appropriate, lifelong learning approaches. The individual's personal characteristics must be taken into account as well as their levels of functionality, other disabilities and different possibilities of the environment, in order for the treatment plan to be individualized. A personalized treatment plan according to the needs of each individual as well as the needs arising from the disorder itself, should be created by a trained interdisciplinary team and include the perspectives and goals of all involved.

Currently there is no treatment that is able to cure ASD but through studies and practice several interventions have been developed in order to be used with young children. Those interventions may reduce symptoms, improve cognitive ability as well as maximize the ability of the child to function in the society by improving daily life skills. (Dawson et al., 2012, Reichow, Hume, Barton, & Boyd, 2018) ASD affects people in different ways and that means that it needs to be treated differently considering every individual's needs. Therefore, treatment plans are multidisciplinary. Most early intervention approaches focus on psychotherapy, some involve the child's guardians. Also structured special education interventions seem to be very effective.

Most behavioral intervention strategies focus on the development of social and communication skills, especially on a young age, when children show challenging behaviors and restrictive/repetitive interests. According to CDC (2015), medical and dental exams should be a consistent part of the child's treatment plan. A child with ASD may show

symptoms that at first look like ASD symptoms but in reality they might be something health related that they cannot comprehend and can not express it with a different way. For instance, head banging could be an ASD symptom, or a sign for headache. It is therefore extremely important to incorporate frequent check-ups and thorough physical examinations when a child is showing such symptoms that could be either this - or that.

Parental counseling is a crucial and necessary intervention, as the diagnosis of the syndrome can confuse them, which in turn leads them to turn - often misinformation from sources such as the Internet. Parents need proper guidance and information about the quality of interventions and their suitability for each autistic child. After all, as already mentioned, every case of an autistic child is and should be treated differently. Each approach has different views on the elements that come from the family and compose vital data on the planning of each therapeutic intervention.

CDC includes four different types of treatment approaches currently available. Behavior and communication approaches, dietary approaches, medication and complementary and alternative medicine. Generally, all treatment programs work towards minimizing the disruptive effects of learning with an ASD and maximizing the benefits through gained skills. Treatment goals need always to be updated as they might change according to age and developmental level of the individual with the focus always remaining on the social, language and self help skills, which is the most crucial part in most treatment programs. Early screening can be done as soon as the child is 18 months or during the early preschool years. Also, more cognitively able children might be missed while screening on such a young age. Early diagnosis and assessment are important to optimize the potential for a good outcome (McClure and Melville, 2007; Volkmar et al., 2014a).

An important step towards treatment for everybody with ASD was the advent of the Education for All Handicapped Children Act, which commanded education as a right for children with special needs. (NRC, 2001) In conclusion, early intervention is the only proven method that makes a big difference in most children's lives as it leads to early detection and diagnosis as well as allow the children to make substantial gains.

Most treatment programs for autism aim at the full utilization of the existing potential of the child and the support of himself and his family in order to deal as effectively as possible with the difficulties arising from the disorder (Kakouros & Maniadakis, 2002 ).

#### **4.1. Dietary approaches**

Taking into account the limited available treatments in improving the ASD core symptoms, many families focus on different dietary approaches, as a low risk treatment for autism. There has been little to no evidence that supports that the use of nutritional supplements and special diets can limit or treat ASD symptoms. However, there has been a limited evidence and understating towards such approaches and their safety as well as the way that they might affect behavior. (Sathe, N., et al. 2017)

It has been believed that autistic individuals may have an altered metabolism of or gluten and casein proteins, and that may affect their behavior. Therefore a gluten free, casein free diet (GFCF) together with various vitamin supplements has been followed by many families in order to seek potential behavioral intervention for their children with ASD, without a clinician's input. (Wong HH, Smith RGA, 2006) A systematic review of 19 control trials (Sathe, N., et al. 2017) has proven that there is not enough evidence to prove that theory. Overall, short term studies of specialized diets and the use of nutritional supplements were examined and provided limited conclusions about their effects in the behavior of children with an ASD.

Clinicians and registered dietitians are competent and can advice whether a child's diet need to be changed in order for them to grow and develop properly. ("Treatment | Autism Spectrum Disorder (ASD) | NCBDDD | CDC", 2019)

#### **4.2. Medication**

As a fact, there is no medication available that can completely treat the core symptoms or cure ASD. ("Treatment | Autism Spectrum Disorder (ASD) | NCBDDD | CDC", 2019) Medication can be helpful in cases where the individual has another comorbid condition as it can help individuals function better and manage certain behaviors such as potential hyperactivity, seizures, depression, anxiety, inability to focus, behavioral reactivity and self-injuries. Minimizing those symptoms can allow individuals with autism to focus on other development areas, like learning and communication.

Many different professional practices are involved in the treatment of ASD and the available literature varies and that has as a result considerable differences in research findings. A number of researchers (McDougle et al., 2005) have found while testing the

effectiveness of risperidone, an antipsychotic drug that while it might be effective in the repetitive and stereotyped patterns of behavior, it makes no difference in the social interaction and communication area while sometimes side effects of medication makes it less useful. The FDA has approved the use of risperidone for patients 5 to 16 years old and aripipazole, for patients 6 to 17 years old, as a way to treat irritability. Nevertheless, medication does not affect everyone the same way and carry risks or even overlap with other disorders such as attention deficit hyperactivity disorder (ADHD). ("Be Aware of Potentially Dangerous Products and Therapies that Claim to Treat Autism", 2019)

Mediations such as selective serotonin re-uptake inhibitors (SSRIs), tricyclics, psychoactive and anti - psychotic medications, stimulants, anti - anxiety medications and anti-convulsants are generally used in order to treat problems that result from the body's imbalances in chemical systems, obsessive and compulsive behaviors, irritability and hyperactivity, anxiety, panic and seizure disorders that are commonly found in the autistic person. ("Be Aware of Potentially Dangerous Products and Therapies that Claim to Treat Autism", 2019)

Healthcare providers that work with children with ASD and their treatment are the best source of information when it comes to using some sort of pharmaceutical treatment for ASD. The child's progress along with any reactions and side effects of the treatment must be closely monitored and taken into consideration so that it does not affect negatively the progress of the child the benefits of the intervention. According to research, medication interventions have maximized results when used in parallel with other behavioral interventions. (Aman, M. G. 2009)

## **5. Early intervention**

A early diagnosis is the one that can lead to to early intervention which can successfully help the child's better development. Early intervention is a complex form of service, provided by a team of experts, an interdisciplinary team in a natural environment and has a child-centered character. (Drosinou, 2009) Early intervention is the continuation of diagnosis and evaluation. The planning of the intervention and the objectives have already emerged from the evaluation process. More specifically, early intervention is a therapeutic

approach that starts while the child is still in preschool and school. Usually it refers to infants from 0-2 years old as well as to preschool aged children from 3-6 years old.

Early intervention takes place at an age where the young child's brain still has the ability to be formed, meaning that it has better plasticity and can still be formed compared to when the child is older. That gives better a bigger and better chance so that the treatments can have a longer and better effect, giving their children the best chance in order to develop to their full potential that can even lead to go off the autism spectrum when they get older. ("Early Intervention for Autism", 2021)

Due to the ASD's particular complexity, a specialist's intervention is required from a properly trained executive on an individual basis and beyond. Other than that, interventions can actually take place in preschools, schools and specialized day centers alongside other children. Those interventions should continue from phase to phase throughout the person's life, developmental path, needs and peculiarities. The main goal of EA is to gain those early life skills in cognitive, social, emotional and physical areas of child development.

When creating the intervention treatment plan, we must take into account some factors such as: the particular characteristics of the child, the degree of the disorder, the frequency and intensity of the child's problem behaviors, the chosen approach, what goals it sets for the child's development and whether matches the personal style of the educator and the family, the cost of the method and the financial situation of the family and finally what can happen if the goals are not achieved (Cumine, Leach & Stevenson, 2000)

Early intervention is important, but it is not always happening due to many different reasons. Unwillingness of the family, miss-diagnosis or false information from a professional is something possible. Early interventions goal is to help the child and the family to make the best out of the existing methods and receive support through their community as well so they can reach a level where they personally feel satisfaction and where the child can develop to its full potential. On something like that, that involves many different people, feelings and opinions, communication is the key. The child will develop faster when there is a deeper level of communication and collaboration between the families and the professionals.

In Europe, early intervention is a set of services that gets offered to young children and their families following a request at a specific time in the child's life, and provides



special support to the child in order to ensure and promote personal development, strengthen the family competence and support the social integration of the family and the child.

It is especially important to mention that EI does not have an unlimited effect. It is a continuous process that requires to maintain its measures so that the child can safely go through situations that may cause them stress and vulnerability to the children such as moving from preschool to school or changing city etc. Early intervention needs to be maintained over time for some children in order to avoid any drawbacks and to provide long-term, extensive help and stimulation. EI has its focus on facilitating the individual's daily life rather than attempting to cure. Focus is rather drawn into making progress in development and avoiding drawbacks.

### **The role of environment in Early Intervention**

Structured intervention programs for the education of children with special needs show particularly positive outcomes in learning and communication of children with ASD. An important factor that contributes to meeting the needs of the child is the configuration of the classroom and other areas of teaching. Properly structured physical spaces, programs, individual work systems, visual structures and routines are part of such structured programs, which have proven to be lucrative in classrooms for autistic children of all ages and levels of functionality.

Furthermore, a structured physical environment is especially important for children with autism. The continuity and visual cleanliness of the space and its boundaries for specific activities, enables these children to better understand the environment and the relationships that develop within it. Teachers and paraprofessionals working with autistic children need to think carefully about the goals of their classroom and plan ahead for a specific area in the space for each area of activity. Visual and audible stimuli that often distract autistic children should be eliminated, while simple wall decoration is encouraged to eradicate confusion and distraction. A classroom that is very small or does not have enough storage space is not only inconvenient, forcing children to stack on top of each other, but also makes it difficult for them to visually recognize the boundaries of space. The use of educational materials that include familiar objects from the child's environment is just as important at the beginning of treatment. Then, depending on the child's progress, more

complex educational means are used, while the use of visual and auditory stimuli is limited only where necessary, in order to avoid the distraction of the child's attention. Frequent updating of the educational environment is also considered necessary, so that it adapts to the constantly changing needs of the child.

Undoubtedly, a structured, clean and well-planned environment is a key asset to a successful intervention program.

### **5.1. Early Intensive Behavioral Intervention**

The Early Intensive Behavior Intervention is an evidence-based, systematic, structured, appropriate developmental approach designed for teaching pre-school children with autism. It is based on the principles of Applied Behavior Analysis (ABA) and focuses in teaching socially significant behaviors. The intervention should start before the age of 3, should have an intensity of 30-40 hours per week and end after two years in order to achieve better results. This type of intervention has some structural features which are as follows (Klintwall & Eikeseth, 2014).

Both DTT (Discrete Trial Training), meaning one-to-one teaching as well as a more naturalistic and incidental teaching are included in the EIBI approach. One-to-one intervention is a clearly planned and defined learning situation that focuses more on basic skills such as verbal and motor imitation, language development and matching while the less structured teaching works in a more naturalistic way including all areas of development and functioning (Klintwall & Eikeseth, 2014). IT (Incidental Teaching) is based on the child's interests and initiatives while NET (Natural Environmental Teaching) gives the opportunity to the child in unstructured situations to learn through the natural reinforcers of a behavior. (Schreibman et al., 2015).

EIBI (Early Intensive Behavior Intervention) can take place in training centers or institutions, in the homes of children with autism who receive intervention or in a structured preschool-type environment. The intervention is individualized and supervised by specialist therapists and can be performed by them, the child's teacher or parents. In a clinical setting, all interventions and programs are monitored and executed by experienced and trained staff with ABA credentials. Trained staff have the opportunity to access to a home setting intervention, where they will act as supervisors and together with the parents

and the students will conduct the treatment. A school or preschool setting is the most common training environment where EIBI usually takes place for children with ASD. (Klintwall & Eikeseth, 2014) In a school and home setting there is the advantage of a natural learning environment and the benefit of co-existing in a group typically developing peers. That opens up more opportunities for the acquired skills to generalize in other social situations beyond EIBI training.(Lovaas, 2003) On such a community based environment, the treatment is performed by regular preschool staff. This is a major challenge in maintaining the quality of the treatment and reach the optimal intervention outcomes.

EIBI can be used together with other approaches such as visual support and AAC (Augmentative Alternative Communication) that are all integrated in the treatment together with other ABA (Applied Behavior Analysis) procedures. (Wong et al, 2015)

The goals of this type of intervention program are to teach skills that will be essential and challenging for children with autism in every day life, such as imitation and attention retention skills, social and communication skills, while attempting trying to reduce problem behaviors that are quite common in autism such as repetitive movements, attachment to routines, and even self-injurious tendencies. This approach is based on a positive reinforcement, and detects the skills that are lacking from the child, breaks them down into components and teaches this component behaviors in small progressive steps. Approaching the child's developing skills is done by teaching some novel behaviors to the child, that get gradually eliminated later on until the child reaches a level of independency. The complexity of the skills needed to complete different tasks increases, following the child's progression in order to give the tools to the child in order to reach the highest stage which is also the intended goal.

The stimuli used during the teaching should stimulate similar behaviors in the child and not irrelevant, e.g. It is better for the child with autism to mention the word car when he sees one on the street, or when asked if he knows how to describe means of transport, than to say that word in situations that have nothing to do with the stimulus. The correct response of the child with autism leads to either a simple immediate praise or other appropriate reinforcement, while the wrong response leads to error-correction procedures.

Amplifiers used as rewards for children with autism are very important to them but due to the fact that each child is a different personality, teachers need to understand

what each one enjoys in order to offer him the best "prize", the which should not be their "apotheosis" in the social environment as children with autism do not capture or do not take into account this kind of reward. The greatest reward and reinforcement should always be reserved for unprompted, correct responding.

In accordance with recent research (Reichow et al., 2018), EIBI is considered more of a comprehensive program instead of a focused intervention as it encloses a series of focused interventions that focus on the development of a bigger set of skills in the areas of communication, language, daily life skills and engagement with peers.

### **Involvement of family in EIBI**

The active participation of the family is considered necessary to achieve the best possible therapeutic results, as the intervention only in a therapeutic and educational context, no matter how extensive, is not enough. This active participation requires, on the one hand, counseling support and, on the other, systematic training.

The involvement of parents in EIBI is crucial and strongly emphasized as it cultivates a kind of communication between them and between therapists and so many views are exchanged but at the same time both sides are informed about what the child with autism prefers, which methods motivate him to respond to the teaching, what strategies should be implemented, how to reinforce the existing knowledge but also how to generalize with other people in other environments (Copeland & Buch, 2013). The parents should be trained in basic fundamentals of the approach in order to initiate the treatment and help the child further improve and generalize their skills. The close cooperation and communication between the family and the specialists is vital and can lead to a higher success rate of the treatment. Overall, the treatment should be child and family focused, having as a main goal to minimize core autism symptoms and family stress while at the same time improving the overall quality of life for the individual with ASD and for the family involved.

### **Early Intensive Behavior Intervention and Applied Behavior Analysis**

EIBI (Early Intensive Behavior Intervention) uses evidence based procedures that are derived from from the science of ABA (Applied Behavior Analysis). Those evidence based strategies and procedures that are focused in developing one skill are called a program. (Copeland & Buch, 2013).

ABA is an approach that in 1960 began to interventions for children with autism are planned by Ivar Lovvas and colleagues at the University of California, Los Angeles (Rosenwasser & Axelrod, 2001). ABA (Applied Behavior Analysis) is a branch of psychology and is based on the view that it is necessary to understand the reasons that trigger a behavior and then begin the effort to improve this attitude with a properly organized program (Hernande & Ikkanda, 2011). According to the ABA, autism is a set of biological behaviors that present some deficiencies which in order to overcome them must have interactions with the child's natural environment which should include people who will offer this type of interaction (Green, 2001).

## **5.2. The neurological basis of early intervention**

Scientifically based studies related to the development of the brain have shown that to maximize the development of the mind, the work done before the age of three is valuable. The environment in which a child grows up affects both the number of brain cells and its synapses, through which cognitive function develops. In the first years of life, our brain has sensitive periods, which accelerate the learning of the child, while for its all-round development some specific forms of stimuli are required. (Lerner, 1998)

Based on earlier research on early brain development (Carnegie Corporation, 1994):

- i) The environment seems to play a crucial role in the development of the brain, having long-term effects.
- ii) The environment also affects the number of brain cells, their synapses and how they work.
- iii) Even before the first year of life, brain development is faster and wider than previously accepted.
- iv) Early stress seems to have negative effects on brain function in general.

The development neurosciences and brain research can explain how the brain works during early childhood development. Genetic regulation and biochemical procedures in the mother's body are responsible for the prenatal development. During the post-natal development, the environment together with genetics and experiences plays a leading role in the brain development. The brain has great levels of plasticity during the first

years of life but its overall development is a life long process. When a child is born, its brain is prepared for specific types of experiences and can take in basic cognitive processes and sensory perceptual systems. Those experiences are the basis for what comes after and for higher levels of functions. According to the Bucharest Early Intervention Project (BEIP), experience shapes the structure of the brain. Experience is not only something passive, something that just happens on the child, but the interactions between the child and the experiences that are in the environment around it.

Johnston (2004) states that the central nervous system (CNS) has brain plasticity as a prominent feature. Brain plasticity indicates the individual's ability to adapt to environmental changes and to store information in memory. The plasticity mechanisms on the brain and the developing nervous system of a child are so strong that they can be way more influenced by environmental factors than the adult brain. (Johnston, 2009)

We notice that it is very positive to offer a good start to the child, thus providing the opportunities for an advanced knowledge through the creation of brain synapses. A properly enriched environment, the right upbringing and happiness of the child will provide supplies so that the child can reach to its full potential. As promptly mentioned above, for a healthy brain development a child must have healthy experiences. Providing children with experiences that are fundamental for later brain development.

## **6. Dealing with autism in Sweden**

In the Swedish educational system school inclusion is embraced. All students have the same rights when it comes to personal development and learning experiences regardless to functional ability. The National Agency for Special Needs Education and Schools (SPSM) offers to pupils special needs support, accessible teaching material, education in special needs school and government funding.

After a child officially receives a diagnosis of ASD, the family will then be referred to a regional or district based habilitation center. The county council habilitation centers are responsible in offering free support and services as well as they provide treatment and supervision to the families whose children have received an ASD diagnosis. (Socialstyrelsen, 1994). Following the diagnosis, the child and the family will be assigned with a team with professionals that often consists of a psychologist, a special educator, a speech and

language pathologist, an occupational therapist and a social worker. The municipality where the family lives offers extra free support, everyday care and assistance at the preschool, school and even at home. (Skolverket, 2010; Skolverket, 2016; Socialstyrelsen, 1994). Extra funding from the educational authority / municipality is also given to the preschool that the child with ASD is enrolled, in order to employ a para-professional to assist the child on a daily basis.

The publicly funded habilitation centers provide intervention in children with an ASD using a community funded EIBI model. The Swedish board of habilitation centers is the one making sure that the intervention will follow the national recommendations. The recommendations suggest an intervention for at least 35 hours weekly, for a time frame of two years. The intervention should ideally start as early as possible with a high intensity as this is associated with better results. (Föreningen Sveriges Habiliteringschefer, 2012) Thus, in order for the habilitation centers to begin with an official EIBI treatment at school, the preschool and the family need to specify their commitments and come across in a mutual agreement. If all parts come to an agreement to start an EIBI treatment at school, the habilitation centers can provide workshops to the parents and the paraprofessionals working with the child. Moreover, at the habilitation centers, supervision of the EIBI implementation can be offered to the paraprofessionals, school staff and parents in order to guarantee the quality of the intervention. (Roll-Pettersson et al., 2016) The special school is a right and an opportunity for children and adults with developmental disabilities. It is the parents and the child who choose the school form; there is no requirement to choose the special school. If the guardians refuse admission to the special school, the child is entitled to support and help in his or her compulsory school class. There have been cases where parents of children with developmental disabilities have been encouraged to relocate their children to special schools in order to have access to better help resources and greater financial support. A strong pressure from the school must not take place, as the decision is the guardian's and the child according to the Education Act has the right to the necessary support teaching also in the regular school.

### **6.1. Swedish preschools and children with ASD**

In Sweden, the early childhood education lies under the management and authority of the municipalities. There is a tax subsidized preschool system where most children attend, including children with an ASD. The quality of the preschool and the education provided is a very important matter for the Swedish society and it is part of the school system and is based on democratic values. Preschools in Sweden are the first educational step in the education system and follow the preschool Curriculum (LPFÖ18) that states that all children have to be given opportunities to learn science, technology, mathematics, language and communication. The Education Act (2010: 800) states that the education in preschool aims for children to acquire and develop knowledge and values. Preschool should promote a lifelong desire to learn and develop and for all children. The education should also carry respect for the human rights and the fundamental democratic values on which Swedish society rests. According to the National Center for Education Statistics (2017) and Sveriges Kommuner och Landsting (2020) most of the children, including autistic children, between 1 and 5 years attend preschool in Sweden, something that places high demands on the Swedish system in supporting children with and ASD and providing high quality early intervention in the preschool environment. (Magnusson et al., 2014)

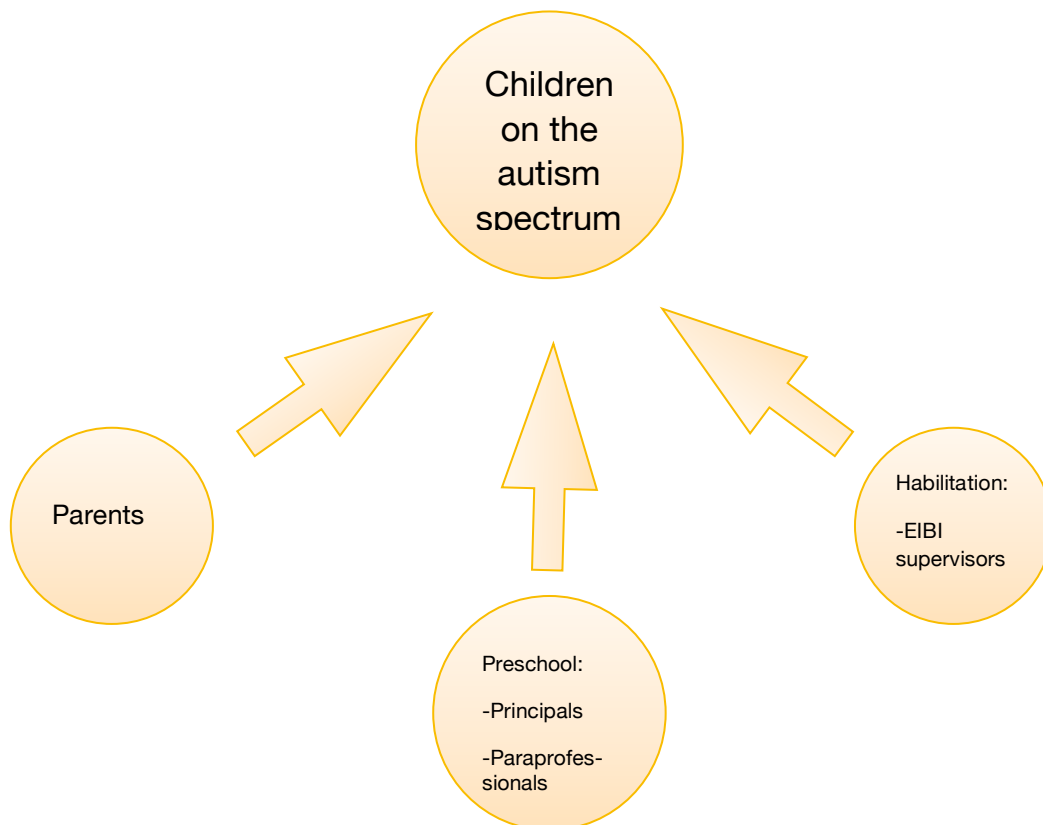
According to preschool policy, all children have the right to receive the support they need for development, learning and participation. Children with special educational needs have the right to either attend a regular preschool unit or a unite with special resources. Neither the national policy documents or the preschool policy documents specify in detail about the kind or organisation or the educational setting and the resources those children are designated to have. The policy focuses more on the long term goals that should be achieved, something that can leave room for interpretation at a preschool and a municipal level about how to organize a more inclusive education and about the accessibility to resources associated to the children's needs.

The Swedish preschool should support the physical, cognitive or other developmental needs of children in need of special support. It is the preschool staff in collaboration with the child's family that can assess as child in need of special support, and a formal diagnosis is not always needed at the first place. (Skollag 2010:800) The national Swedish curriculum for preschools (Skolverket 2016) states clearly that the preschool should include



and support children with special needs by taking into consideration their individual needs. According to Kosidou et.al (2016) the number of children receiving intervention in schools has doubled up between 2011-2016 in Stockholm county.

Figure 1. Overview of stakeholders at organizational and individual level. (Bejnö et al., 2021)



## 6.2. The teacher's role

The teacher is the regulator of the educational process. All teachers play an important role in the inclusion of children with ASD. It is necessary that teachers have the knowledge needed when it comes to ASD because they are the ones open the road to inclusive, sustainable education. As the UNESCO Salamanca Statement supports, there is a commitment to inclusive education for everyone which means adherence to an inclusive rights-based perspective that is associated with a greater presence of students with disabilities, including autism spectrum disorder, in regular classrooms. The current reality is that teachers must have the appropriate knowledge about special needs education and inclusive environments, receive training and the continuous professional development and

improvement of knowledge in order to ensure inclusive and equitable education. (Roberts & Simpson, 2016)

This is because it must at all times implement the appropriate "strategy" as a roadmap for achieving a specific teaching goal. In particular, the role of the preschool teacher is more specialized as he is called to know very well the needs of the children and the special needs of each individual, as well as the interests of the children in his class, so that he can create the appropriate conditions and opportunities for learning. In this way it will be able to effectively help to overcome learning difficulties and meet the different needs of every child.

As a matter of fact, the role of the preschool teacher in the modern preschool is becoming more and more multifaceted and complex. This is because the preschool teacher should appreciate the moral and educational world of the child, as well as the social and cultural context of it's personality, always taking into account those factors that interfere with the child's cognitive development, such as mobility, social and educational environment etc.

Other than that, the general class teacher bears a serious responsibility when deciding to refer a child with impairments in social interaction and communication, and this is perhaps the most important step that can lead to a diagnosis.

In order to detect autism spectrum disorder in a preschool classroom and to deal with it later, the teacher should include some specific elements in his teaching. In particular, throughout the process the teacher should have the ability to perceive the different needs of students in his classroom, to adapt to different models of teaching methodology and to manifest different behaviors on a case-by-case basis, to have a basic knowledge of the normal development of a child and to clearly reflect in his teaching the expectations and requirements from the children. It also requires a thorough planning and programming for both the cognitive and psychosocial peculiarities of these students in the context of general education. A program for students that are in the ASD should include motivational strategies, with specific teaching planning but also the appropriate material and content. Also, the teacher should make immediate adjustments and modifications of the program, so as to take into account the individual differences of students with low performance and their difficulties of response.

The teachers role towards students with school difficulties is particularly reinforcing, in terms of the relationship he/she forms with them, as it influences their social behavior and performance. It evokes a sense of security and promotes the socio-psychological climate of the classroom for a learning process, where it will bring multiple benefits to students. Another role that teachers should play is good communication with parents. An important factor for the success of intervention programs in children that are in the ASD is the regular communication and information of parents about the cognitive and social progress of their children. Besides, we can draw important information from the parents about the developmental characteristics of the children but also about their social behavior.

## **Chapter B. Methodology of research**

### **7. Aim**

Students with autism have been included in recent years in the environment of general education in the Swedish schools with more frequency compared to previous years. Preschools and the state mechanisms that are responsible for organizing them should be equipped with the necessary curricula and experience to work with children with autism in general education classes and provide quality early intervention and support to children with and ASD and their family. Based on the extensive literature review, regarding the experience of general and special education teachers in the education of students with autism and the quality of the early intensive behavioral intervention support programs and their implementation within the support system in Sweden, an attempt is made to gain a better understanding regarding EIBI supports and barriers in the Swedish preschools.

The purpose of this study was to evaluate the attitude of the preschool education system in Sweden regarding the provision of early intensive care to children with autism as well as to clarify the role of the teacher in the Swedish preschool in relation to the inclusion of students with autism in the general pre school classroom.

### **8. Systematic Literature Review**

The methodology followed for the completion of the present work is harmonized with the basic principles of the systematic literature review. Initially, the literature review presupposes the detailed and in-depth search of the relevant researches. This process is

demanding, as various factors need to be taken into account with the ultimate goal of selecting the articles to be included in the review. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) protocol for conducting systematic review is an evidence based minimum set of items for reporting in systematic reviews and meta-analyses. The PRISMA protocol is followed in order to ensure a transparent and comprehensive analysis process that follows the extraction of data. (Moher, Liberati, Tetzlaff and Altman, 2009)

### 8.1. Research Procedure

The database search for this systematic literature review started in September 2021. In particular, starting with the search in reliable databases and electronic libraries such as Psych Info, Gothenburgs University Library, CINAHL and Science Direct. By using the keywords and MeSH terms (Table 1) a number of articles were found. The main criterion that was set to include the research in the review was the clarity of the issue. The selection of surveys was limited to those dating back to the last decade and the main limitation was the age of the children and the location, which should be included in the boundaries of early childhood in the context of the Swedish system. The surveys, which were selected and entered into a process of comparison, rejection or inclusion, were in English and Swedish. The same search words were used in all databases and can be presented subsequently.

- “early intervention OR EIBI OR early intensive behavioral intervention OR ABA OR applied behavioral analysis” AND “early childhood OR preschool OR Swedish preschool OR förskolan OR sweden” AND “ASD OR autism spectrum disorder OR autism spectrum tillstånd”

The participant, interest and outcome (PIO) framework was used in order to highlight the specific components necessary for the aim of this review.

*Table 1. Search Terms*

Diagnosis	Age range / Location	Intervention	Outcomes
“ASD”	“Early Childhood”	“Early Intervention”	“Quality”
“Autism Spectrum Disorder”	“Preschool”	“EIBI”	“Knowledge”

“Autism Spectrum Tillstånd”	“Swedish Preschool”	“Early Intensive Behavioral Intervention”	“Teachers”
“Autism”	“Sweden”	“ABA”	“Förskollepersonal”
	“Barn”	“Applied Behavioral Analysis”	“Barriers”

The final selection of articles was followed by their analysis and systematic review. At this stage it is not enough to simply list them, but the research should be grouped based on the individual issues, the methods followed and their results, with the ultimate goal of drawing valid conclusions. This course was followed and the results were methodically examined, whether they converge or contradict each other and in which individual issues. The correct and comprehensible presentation of the research findings was one of the main goals, as it gives the reader the information he needs about the location of the research on this topic, without having to search and study all the articles used. The presentation of the results was done in individual thematic parameters so that the information is developed clearly and in detail.

The conclusions drawn from the composition of the studies were especially valuable because they have shown us where the scientific knowledge is in relation to our subject and can help in the subsequent planning for dealing with children with ASD in Sweden, whether it involves therapeutic interventions or even state planning. In the end, gaps and omissions were identified in the research of the subject and new research questions were proposed, a fact which is a great gain since it can thus give reasons or stimuli for further research.

## **8.2. Limitations and inclusion/exclusion criteria**

As the focus of the research is on the provision of early intervention services in Swedish preschools and the attitudes of professionals working with these children, the research is largely limited to the Swedish population and to preschools only. Further focus is given to EIBI interventions and the cooperation of preschools and habilitation centers in order to find the gap in the services provided.

Inclusion and exclusion criteria were also used for screening of data regarding intervention strategies, location, age of children, and professionals involved and were established based on the research questions. Firstly, there is a need to investigate the form of early intervention support that the Swedish preschools in collaboration with the habilitation centers provide to the children with ASD, all in aim to discover barriers and room for improvement in supporting preschool children with ASD within the Swedish system. Studies targeting preschool aged children (1-6 years old) with ASD were included, as well studies that focused on the community-based preschool intervention program quality, the preschool classroom environment quality as well as on the knowledge level of professionals working with with preschool aged children with ASD in Sweden. A possible extraction form with inclusion and exclusion criteria is shown in the Table below. (Table 2.).

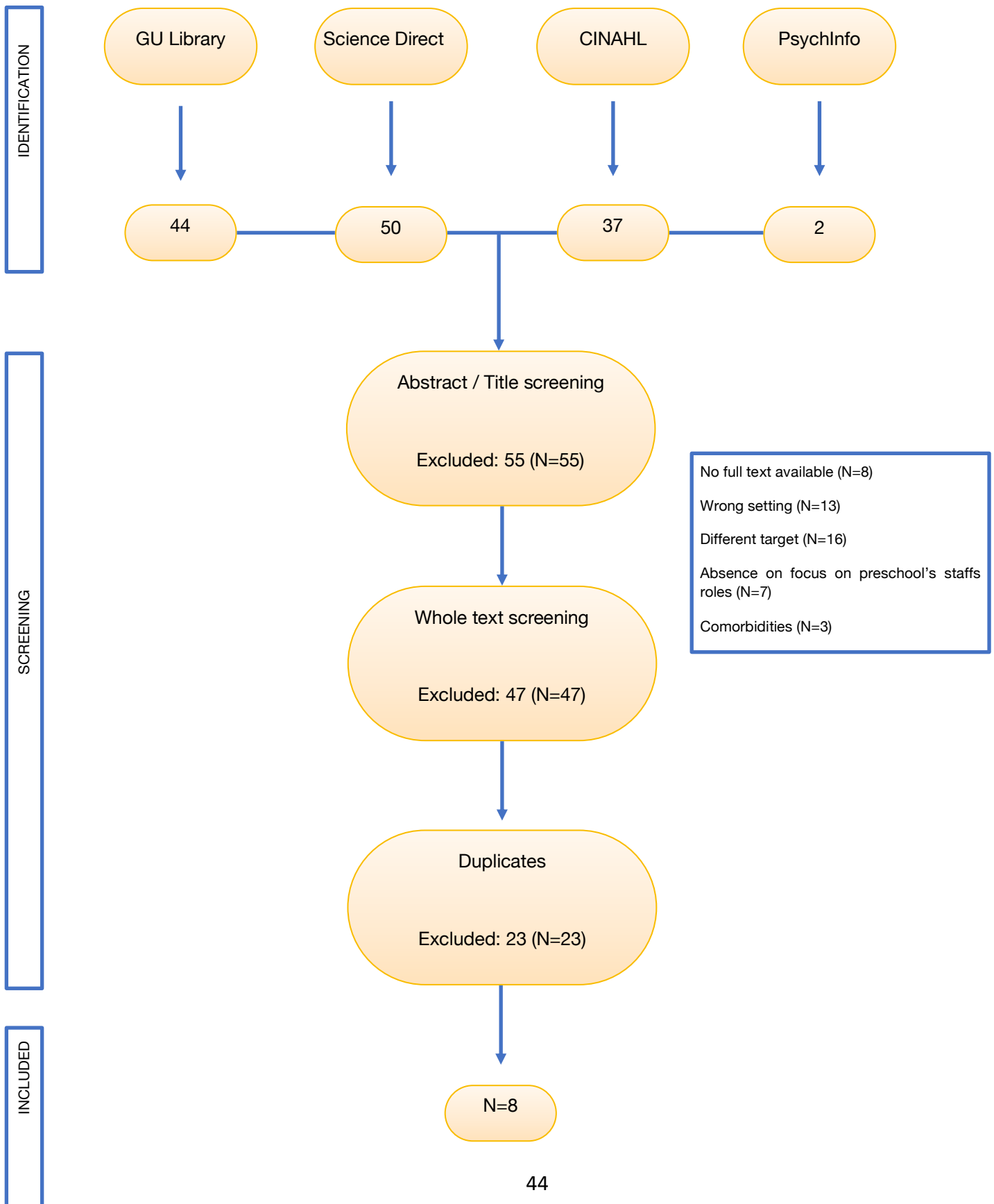
*Table 2. Presentation of the Inclusion and Exclusion criteria applied through all the studies' examination stages.*

	<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
<b>Population</b>	Children aged 1-6	Infants 0-1
		Children over 7 years old
	Children with an ASD	Typically developing children
	Swedish community preschools	Preschools outside Sweden
	Swedish private preschools	Swedish schools
	Teachers and paraprofessionals	Parents
<b>Interest</b>	Autism Spectrum Disorder	Other syndromes
<b>Outcome</b>	Quality early intervention services at school	Early Intervention services at home
	EIBI or ABA procedures	Other EI procedures
	Inclusive preschool environment	School-parent collaboration
	Collaboration between professionals	
<b>Publications</b>	Research articles and studies published in peer review journals	Book chapters, reports that are not peer reviewed
	Qualitative studies	
	Quantitative studies	
	Systematic reviews	
<b>Year</b>	2012-2021	Older research
<b>Caregivers</b>	Teachers	Parents
	Paraprofessionals	
<b>Intervention</b>	EIBI or ABA conducted at preschool settings	Other type of intervention conducted at preschools or at home

### 8.3. Data extraction

There were 133 studies matching the search threads that were used in the databases. Specifically, in PsychInfo website, the search resulted in 2 articles, while in Gothenburgs University Library website search, 44 articles were available. Later on, in the Science Direct website search, 50 articles were found, while in the CINAHL search, 37 articles were found. Total 133 articles were extracted from the databases. After carefully examining all articles in the primary examination on title and abstract level based on the inclusion and exclusion criteria set, 78 were excluded from the further analysis, mostly due to being duplicates or due to different target and method of early intervention (e.g. play or music intervention instead of EIBI) or wrong setting (health and home settings instead of school settings), leaving 55 articles for secondary full text examination. Inclusion and exclusion criteria were again applied to all articles included for full-text screening process. During this screening, the focus was largely on the method section where the process of the early interventions were described, since the goal was to evaluate the attitude of the preschool education system in Sweden regarding the plan of providing early intensive care to children with an ASD as well as to clarify the role of the teacher in the Swedish preschool in relation to the inclusion of students with autism in the general pre school classroom. Finally, from the 55 remaining articles, more articles were excluded since they were not for the study, due to different aim and intervention focus, unspecified early intervention methods, presence of comorbidities, completely different target and absence on focus on the preschool's staffs role. After the exclusion of 47 articles, 8 remained for data extraction. The screening process summarizing the procedure followed is pictured in the PRISMA flow diagram below, which depicts the flow of information through the different faces of the systematic review.

Table 3.  
Flow diagram showing the research procedure.





#### 8.4. Research data analysis

Analyzing the data is the final step of the methodology and was executed during and after the extraction of the data. Each study has a reference number that is used through the whole procedure of the data analysis, as shown on Table 3. The general information about the studies and the intervention program as well as the the procedures performed and measures taken in Swedish preschools in order to provide support and intervention in children with ASD, were analyzed in order to get an overview of the different tools and processes that were followed while aiming to support and include children with ASD in general education classrooms in the Swedish preschools.

Later on, a thematic data analysis was used in order to identify and reveal patterns in meaning across the data. This qualitative data analysis was used in a set of texts to identify research questions, common themes and topics, ideas and patterns of meaning that were repeatedly presented in the databases. This process led to the results of this review.

#### 8.5. Importance of research

The importance of research is related to its current trends inclusion and increase in autism diagnoses, factors that affect preschool in general. However, little is known about the experience of general and special education teachers as well as paraprofessionals working with children with an ASD, their knowledge of ASDs and EIBI, and the support system and practices from the government organizations such as rehabilitation centers that are responsible for supporting children with an ASD in the Swedish preschools.

In theory, the present research is of scientific interest, as it helps to clarify concepts about inclusion, ASD and strategies that are scientifically substantiated for the successful inclusion of a student with autism, such as EIBI and ABA and lastly points out the gaps and barriers in the Swedish support system for children with an ASD and opens up room for improvement.

*Table 4. Overview of articles*

N*	Name	Author / Year	Methodology	Aim	Results
	A didactic perspective on negotiations and collaborations between different actors within the Swedish support system: children with autism spectrum disorders included in community-based preschool settings.	Ingrid Olsson, Lise Roll-Petersson / 2019	Qualitative case study	To examine inter-organizational collaborations between preschools and habilitation centers concerning intensive behavioral interventions for children with ASD in inclusive settings in Swedish preschools that provide high-quality early intervention to children with ASD.	The preschool placement for children with an ASD is inclusive, but their education can be described as often taking place a bit “on the side”. Preschools and habitation centers would actively cooperate contributions to how the intensive behavioral intervention would be arranged at the preschool, something that was proved crucial for the children’s learning.
	Allegiance and knowledge levels of professionals working with early intensive behavioural intervention in autism.	Ulrika Långh, Martin Hammar, Lars Klintwall, Sven Bölte / 2016	Allegiance to the ABA treatment supports the ABA treatments efficacy. Lower levels of allegiance are associated with less hours spent of the actual intervention and that affects negatively the intervention outcome.	To survey the levels of knowledge about and allegiance towards EIBI for children with ASD.	There needs to be an improvement regarding formal knowledge levels of preschool staff who work with children with an ASD by delivering EIBI interventions as well an improvement regarding levels of allegiance towards EIBI among non-experts. Behavior modification techniques knowledge should be added to university curriculum for preschool teachers.

	<p>The efficacy of intensive behavioral intervention for children with autism: a matter of allegiance?</p>	<p>Klintwall L, Gillberg C, Bölte S, Fernell E. / 2012</p>	<p>Pilot study</p>	<p>To examine the hypothesis that the allegiance of trainers is important for early intervention treatment gains in preschoolers.</p>	
	<p>Inclusion of preschool children with autism in Sweden: attitudes and perceived efficacy of preschool teachers</p>	<p>Rano Zakirova Engstrand, Lise Roll-Pettersson/ 2014</p>	<p>Pilot study</p>	<p>To examine the relations among preschool teachers' attitudes towards the inclusion of children with ASD and teachers' work experience and educational background that work in Swedish preschools.</p>	<p>Preschool teachers held positive attitudes regarding the inclusion of children with autism, something that is related to the numbers of credits they had in special needs education. Furthermore, half of the preschool teachers admitted to use ABA practices. One to one support was limited to 2.56 h/week, much less than the recommended in behavioral based intervention practices. Insufficient knowledge of autism together with lack of supervision, questions the quality of early intervention.</p>

	<p>Enriched supervision to increase quality of early intensive behavioral intervention in autism: a pragmatic randomized controlled pilot study</p>	<p>Ulrika Långh, Élodie Cauvet, Adrienne Perry, Svein Eikeseth &amp; Sven Bölte / 2017</p>	<p>Pilot study</p>	<p>To examine the provided quality of EIBI on children with ASD when conducted in a community preschool setting from preschool teachers.</p>	<p>When supervised, the quality of EIBI delivered in the preschool environment is controlled and increased.</p>
	<p>Adapting the preschool environment to the needs of children on the autism spectrum in Sweden: A quasi-experimental study.</p>	<p>Hampus Bejnö, Lise Roll-Petersson, Lars Klintwall, Ulrika Långh, Samuel L. Odom &amp; Sven Bölte / 2021</p>	<p>Pilot study</p>	<p>To examine the quality of the preschool learning environment for children on the autism spectrum, along with outcomes for these children, and their preschool staff, using the Swedish Autism Program Environment Rating Scale (APERS-P-SE).</p>	<p>The quality of the preschool learning environment improved with the use of the APERS-P-SE scale in EIBI preschools. However, improvements in behavior for children and impact on preschool staff applying EIBI were not significant.</p>
	<p>Bridging the Research to Practice Gap: A Case Study Approach to Understanding EIBI Supports and Barriers in Swedish Preschools</p>	<p>Lise Roll-Petersson, Ingrid Olsson, Shahla Ala'i-Rosales / 2016</p>	<p>Qualitative &amp; quantitative study</p>	<p>To examine the barriers and supports within the Swedish service system that might affect the implementation of EIBI practices to children with ASD.</p>	<p>Limited involvement of others is limited and the paraprofessional with the child become isolated. Preschool staff had limited knowledge and skills regarding ASD. Lastly, differences on guidelines and theoretical frameworks between the habilitation centers and the preschools affected negatively the implementation or evaluation of EIBI in preschools.</p>

	<p><i>From someone who may cause trouble to someone you can play with: Stakeholders' perspectives on preschool program quality for autistic children</i></p>	<p>Hampus Bejnö, Lise Roll-Pettersson, Lars Klintwall, Ulrika Långh, Samuel L. Odom &amp; Sven Bölte / 2021</p>	<p>Quasi-randomized, qualitative study</p>	<p>To gather perceptions of stakeholders to autistic children receiving EIBI concerning key program areas that have been positively influenced by the APERS intervention such as staffs competence, children's inclusion and participation, collaboration and the learning environment.</p>	<p>High competence levels among preschool and habilitation staff, a systematic and structured work in supporting and including the children with ASD in the general classroom as well as a collaboration between staff and parents and a adaptation of the immediate learning environment in the needs of the autistic children is needed in order to provide a high quality early behavioral intervention for children with an ASD.</p>
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## 9. Overview of the results

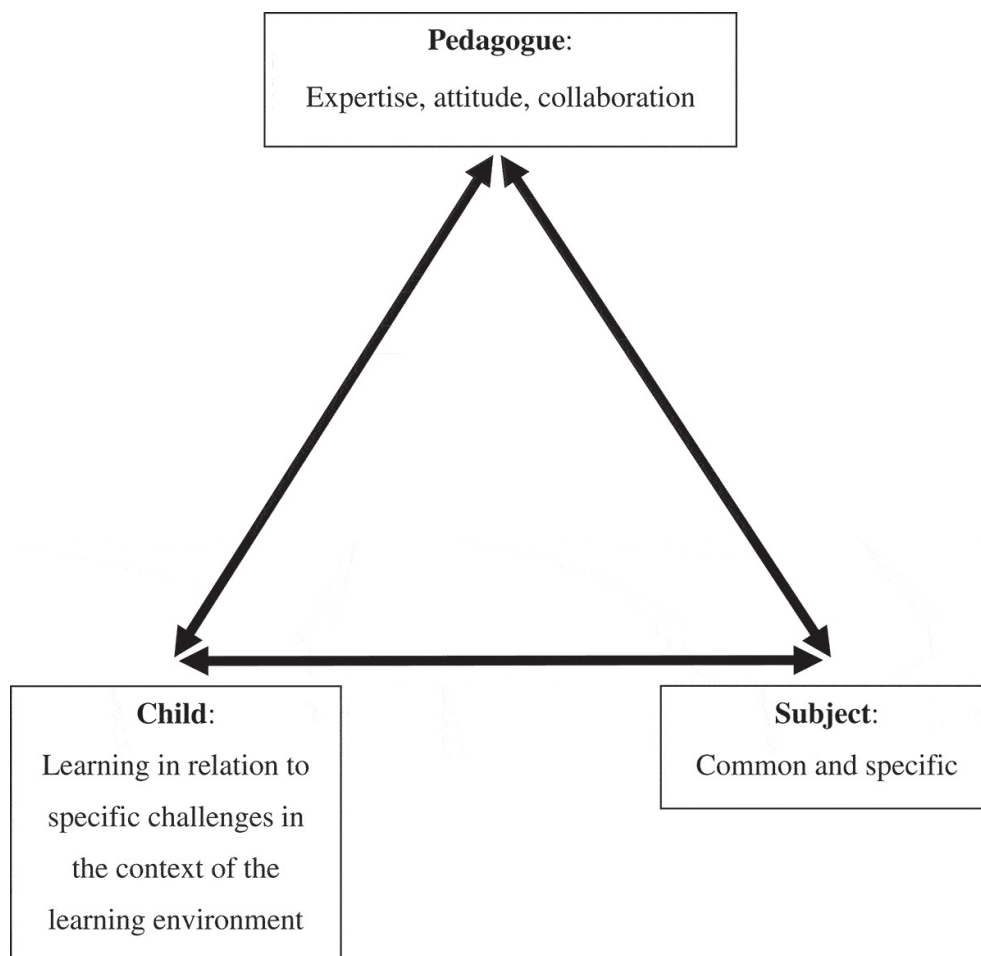
Seven articles have identified to fulfill the inclusion criteria and answer the research questions regarding the attitudes of the preschool education system in Sweden regarding the provision of early intensive care to children with autism as well as the role of the teacher in the Swedish preschool in relation to the inclusion of students with autism in the general pre school classroom. The research questions get responses by observing, comparing and combining the result of the data. An overview of the studies with the most important information is listed above in Table 3. The studies' content information as well as their methodology and results are presented below.

### 9.1. Interorganizational collaborations

According to the didactic theory, (Gidlund & Boström, 2017), the student cornerstone, the teacher cornerstone and the subject cornerstone interact with each other in order to build the didactic triangle. Based on the didactic triangle, everything is of importance in every point while in the process of teaching and learning a concept. Olsson's & Petersson's

(2019) research, used the didactic triangle in order to understand the factors that affect the implementation of behavioral intervention in Swedish preschools. A case study in two Swedish preschool where one child with ASD was included in the typical preschool classroom (1) used the didactic triangle in order to understand how the collaboration between preschool and the habilitation centers is organized in order to support the child with an ASD.

Figure 2. Theoretical model of the didactic triangle when children with ASD receive intensive behavioral intervention in Swedish preschools. (Ingrid Olsson & Lise Roll-Pettersson, 2020)



Collaboration between different organizations that work actively with children with an ASD such as preschool staff, paraprofessionals and the habitation centers has been of vital importance for a quality rich implementation of EIBI procedures to children with autism in community based Swedish preschools. According to Olsson's & Petersson's study (1), it is unclear which organization, meaning the preschool staff or the habilitation center,

is responsible to adapt their practices in order to meet the autistic child's individual needs. The habilitation centers are the ones providing the guidelines according to evidence based practices and the preschool staff is responsible for implementing them and adapting the class environment in order to fit with the child's needs, something that was proven to be hard to implement as preschool staff lack of necessary knowledge and skills in order to adapt that advice to the preschool settings. Adherence in EIBI and holistic implementation of it can be negatively influenced by the differences in terminology used, as the habilitation centers use a more medical terminology and the schools a more educational one. [7]

Supervision from the habilitation centers to the preschool staff working with children with ASD was proven to have positive benefits in the development of evidence based intervention strategies while supporting children with ASD. (1) It has been noticed that such supervision did cause lowered self-determination to preschool staff. That can cause that the habilitation centers provide knowledge and the preschool staff just follow instructions instead of making their own decisions. However, in cases where the preschool staff did not know on how to implement a specific practice even though they recognized that something is a challenge, the habilitation center would provide guidance based on the applied behavior analysis, something that led to successful outcomes and improved behavior adaptation from the child with an ASD.

By the same token, a recent study (Bejnö, et al. 2021) [8] has proven that not only supervision can lead to successful outcomes, but also on-site coaching is needed in order to maximize them. In that study [8] preschool staff experienced that when they receive on-site practical coaching and feedback in the preschool setting about how they work and approach children with ASD is much more helpful rather than receiving theoretical supervision at the habilitation center. The habilitation center staff's thoughts on this matter are ambiguous as some experts experience themselves as lacking the competency needed so that they can teach the EIBI method and other evidence based practices to the preschool staff in the context of regular preschool activities. On the other hand, some habilitation center members have mentioned that on-site coaching can be very challenging due to some staff's sick leave and turnover in the preschool plus occasionally unwillingness of the staff and restricted available time. Not only that, some habilitation center members observed that there was an uncertainty among preschool staff about their roles and

responsibilities, and mentioned that the staff expected the habilitation center experts to set inclusive goals instead of them. [8]

According to the didactic triangle, when it comes to inter organizational collaborations, the habilitation centers are responsible for defining subjects and methods of teaching as well as understanding every individual child's approach to learning. On the other hand, the preschool is responsible for adapting the habilitation center's input and teaching the children with an ASD while meeting their needs within the terms of inclusive education. Nilholm & Göransson (2017) and Nilholm and Alm (2010) point out the risk of inclusion stopping only at placing the child with an ASD in a class with typically developing peers without adjusting the preschool environment and the didactic practices. According to their research, more insight needs about the exact practices that are used in the Swedish community preschool when it comes to adapting the preschool environment and the didactic practices in order to include children with an ASD. Olsson & Petersson point out that the habitation center together with the parents have a strong influence on the subject cornerstone and choices within the preschools. That raises up concerns about how can the education in the preschools be inclusive when another organization has influence on the practices used on the children with an ASD.

It is of great importance to evaluate the progress of the child, especially within the framework of early intensive behavioral intervention. A complication in the evaluation process due to lack of time has also been noticed and negatively affected the inter organizational collaborations. Follow ups and evaluation processes need to be done different places in order for the power to be distributed to all coordinators of the behavioral intervention so that everyone's expertise can be utilized as well as in order to have more meaningful evaluations. (1)

There is an overall need to adapt the way we view children with ASD. A focus on the child cornerstone from the didactic triangle is needed and a few of children with an ASD as special learners instead of children for whom we need to adapt our teaching strategies due to their ASD. (1) Concluding, the country's habitation centers, municipalities, preschools and preschool staff need to improve the preschool learning environment quality for children with special needs in order to be able to use evidence based practices like EIBI with children in the ASD spectrum.



## **9.2. Allegiance towards EIBI**

EIBI (Early Intensive Behavioral Intervention) is a behavior modification method which is globally used and based on the the principles of ABA (Applied Behavior Analysis). The EIBI targets deficits or excesses in behaviors and improves basic or more advanced sets of skills and can already start from he early childhood year, is executed mostly in the child's natural environment and has an intensity of 20 to 40 hours weekly on a timeframe of 2-3 years. That form of intervention has as main characteristic positive reinforcement of the child and a systematic usage of prompts in many different learning opportunities in order to teach the child how to independently master a skill and perform a task without failure. (Klintwall L, Eikeseth S., 2013) EIBI can be delivered in different environments such as clinical environment, home settings or school environment. In Sweden it is common that EIBI interventions are delivered in school settings by regular preschool staff, something that can be seen as positive because the skills gained in such a natural learning environment will be able to generalize to social situation beyond the EIBI training. In such cases, a challenge always is to maintain the quality and consistency of the EIBI intervention, since it is not performed by experts on the field of special needs or EIBI.

Research has shown (4) that preschool teachers in Sweden, working in community settings with children with ASD do not acquire the knowledge needed regarding ASD and ABA, since those subjects are not a fundamental part of the higher education for preschool teachers. When it comes to EIBI, teachers earn the knowledge and skills needed while they are conducting the intervention and the program is up and running. The quality of the EIBI provided is questioned, since the staff that runs the intervention is usually not a permanent member. Furthermore, the person who works the closest with a child with an ASD is hired by the municipality as a "personal assistant", following the assessment of the child with an ASD, having no basic formal qualification demands. That means that the personal assistant may be an unqualified unemployed young adult without the ASD and ABA knowledge and experience needed to work with a child with an ASD, something that affect the intervention provided and the child itself.

Under those circumstances, it is of highest priority that the intervention provided in the Swedish preschools is supervised and monitored. Practical and theoretical

supervision as well as allegiance towards the method applied is needed for the purpose of a successful treatment outcome. (McLeod BD., 2009) Similarly, a pilot study focusing on the allegiance of preschool teachers towards the efficacy of the ABA treatment in preschoolers (3) showed that in EIBI-trained staff that had high allegiance towards the training principles of EIBI effected positively their autistic students, who showed positive adaptive skill outcomes. In the same study (3) preschool staff that received supervision and theoretical knowledge of EIBI experts, showed higher levels of knowledge and allegiance towards the intervention itself, something that increased its quality. EIBI trained preschool staff are found to have more allegiance towards EIBI than non trained preschool staff, but still less allegiance than EIBI experts. Thus, due to the training principles of EIBI, including the high intensity and the structure, being very specific, it is very important to fit in with the professional's teaching philosophy and work style. A struggle of identification with the EIBI technique has been noticed among professionals. (3).

### **9.3. Preschool teacher's attitudes towards inclusion of children with ASD**

Including a child with Autism spectrum disorder in general classrooms can be a real challenge for preschool teachers. Luttropp et al. (2007, p. 23) notes that "Although the majority of Swedish children in need of special support are included in mainstream preschools, the challenge for teachers is actually to integrate these children into the everyday activities, relationships, and routines of the preschool. Another challenge for preschools is to realize that they have to consider the needs of individual children by creating activity settings in which children can use their abilities, interests, and experiences to increase the level of sustainability of intervention" As shown above, the role of the teacher is vital and influences the quality of the intervention program offered in regular preschool settings as well as creates an inclusive preschool environment.

Having a negative attitude towards children with ASD and early intervention can be a barrier to their successful inclusion. Therefore, the teachers' positive attitudes are much needed. A study conducted in 63 municipal driven preschools and 2 elementary public schools around Stockholm County, Sweden, that examined the preschool staff's attitudes towards inclusion of children with an ASD in the general classroom [4] found out that teachers who took special education courses and worked with children with an ASD were

holding positive attitudes towards inclusion in general. It was found out that those teachers did actually hold positive attitudes towards inclusion but did as well hold neutral attitudes when it came to including the children with ASD in general education classrooms. Similar to that, a study conducted in the USA (Park, Chitiyo, & Choi, 2010) have proven as well that teachers with a higher level of knowledge in special needs and pre-service training on the field held more positive attitudes towards the inclusion of children with special educational need, much more than their colleagues with a lower knowledge level.

Another research by Zakirova Engstrand and Roll-Pettersson (2014) that studied the attitudes and perceived efficacy of preschool teachers working with children with autism in Sweden, showed that only 14% of the teachers that participated in the study have received adequate theoretical knowledge during their graduate university training about working with children in autism in a preschool environment and about 50% of the teachers had no knowledge regarding special education or any pre-service on the field, something that can explain their neutral attitudes towards inclusion of children with ASD in the settings of the general preschool classroom. The same insufficiency of theoretical and practical knowledge of the basic principals and procedures on ABA can be found in most professionals working on the field. (Roll-Pettersson & Ala'i-Rosales, 2009)

However, supervision from experts on the field can reimburse for the lack of knowledge from the teachers themselves and that can lead to more favorable attitudes towards children with an ASD. Other than university education and supervision from experts, there seems to be more factors that can affect the preschool teacher's attitudes towards children with ASD and their inclusion. Such factors are the administration's support, availability of resources and close collaboration with other parties is deemed necessary as a means to more inclusive attitudes from preschool teachers. [4] A 2017 study [7] by Roll-Pettersson, L., Olsson, I., & Ala'i Rosales, S. Has shown that preschool staff lack of experience and formal education in working with children on the ASD spectrum, are not well informed and hold a negative attitude towards EIBI and a neutral negative attitude towards including children with an ASD to the context of a mainstream classroom.

#### **9.4. Swedish preschools and Early Intensive Behavioral Intervention**

Despite the guidelines a recent review by The Swedish Schools Inspectorate that has examined the preschool's work with children in need of special support shows that there are

large quality differences in how preschools work with special support. Many preschools do not have sufficiently developed working methods and routines for working with children in need of special support. (Skolinspektionen, 2017) Two thirds of the preschools are estimated to have less well-developed working methods, while only one third were found to provide adequate support to children in need.

The new Swedish curriculum for preschools that was introduced in 2019 focuses more on the preschools obligation and responsibility to support children with special needs in order to promote their optimal development. The preschools and the habilitation centers are the ones that are responsible in accommodating the needs of children with an ASD. However, the outcomes of EIBI for children with autism in mainstream, poor quality preschools and learning environment that are lacking basic knowledge and support, seems difficult and is more likely to fail.

In order for professionals to provide EIBI interventions, they need to have an international quality assurance, coursework meeting the BCBA (Board Certified Behavior Analysts) or BCaBA (Board Certified Assistant Behavior Analyst) standards and RBT (Registered Behavior Technician). Those professional university course content are issued by the Behavior Analyst Certification Board (BACB; <https://bacb.com/>) and provide certification to preschool teachers on a degree level. Nonetheless, Sweden does not officially recognize this clarification system despite the ingrowing interest on it. On a research published at the Journal of Autism and Developmental Disorders (Keenan et al., 2015) there is currently a deficiency in university based graduate training programs. Stockholms University is the only educational institute in Sweden that provides training to professionals that work with children with autism, such as special educators, speech and language pathologists, occupational therapists, psychologists and social workers. The education provided by Stockholm University meets the BCBA standards.

In Sweden and all Scandinavian countries, the programming of and supervision of EIBI follows national guidelines and recommendations (Föreningen Sveriges Habiliteringsschefer, 2012). The habilitation centers use evidence based training models such as DTT (discrete trial teaching), natural environment training and incidental training and are the ones providing supervision to the para-professionals that work with individuals with ASD, the families and the child itself. However, the habilitation centers have little to no control

of what is actually happening on the preschools and at home in terms of structured, organized interventions that follows the EIBI and ABA guidelines. According to a recent study by Långh et al. (2020), preschool staff has little to no knowledge of ABA and EIBI and may receive therefore a couple of hours of in service training and follow up meetings from the country's council clinicians. That constitutes a big challenge for the quality of EIBI provided in preschools and that is the reason why a lot of focus is turned to supervision and quality control of the intervention provided. [5]

On the same note, Zakirova, Engstrand and Roll-Pettersson [4] have found in their study a lack of implementation of early intervention practices in preschools in Sweden, with teachers working in one municipality with children with ASD reporting that the children received an average of 2,56 hours a week of DTT (Discrete Trial Training) or in other words, one-to-one support.

A very recent study (Benjö et. al. 2021) that recognized the need for improvement within the Swedish preschool environment [6], aimed to promote the quality of the Swedish preschool learning environment that provides intervention to children with ASD, by using the Swedish Autism Program Environment Rating Scale. (APERS-P-SE) The APERS scale assesses the quality indicators of programs for children and youth with ASD. The Swedish version of the APERS scale was used in Swedish preschools in order to assess the learning environment and to point out areas that need development while intervention planning. Results showed that the APERS-P-SE based model applied in addition to the EIBI in Swedish preschools, significantly improved the learning environment for children with ASD, especially in the areas of the organization of the immediate preschool environment, the preparation for transitions between activities and routines and last but not least an improvement was noticed on the child's overall independence. Another outcome of the implementation of the APERS-P-SE model is presented in the last study of the literature review (Benjö et. al. 2021) [8] where positive changes were observed in the children that would engage more with other staff and peers, and with the staff themselves that would report more confident in implementing EIBI.

Concluding, detailed supervision among other variables such as knowledge of and allegiance towards ASD and EIBI, the child's characteristics and the family's support are off

substantial importance for a successful intervention. As a result, better quality in intervention predicts better outcomes. [5]

### **9.5. The role of the paraprofessional**

For pre-schoolers with ASD, early intensive behavioral intervention is important as it can lead to a life full of opportunities and an advanced ability to make choices as well as enhance the feeling of belonging instead of having minimal control over life and institutionalization. (Petersson, Olsson, Rosales, 2016) [7] Therefore, infrastructure within the Swedish preschools and a great foundation for conducting EIBI interventions is needed. All interested parties in the autistic child's immediate environment state that a paraprofessional is essential as overall support for the child's learning, development and inclusion. [8]

A case study by Petersson, Olsson & Rosales (2016) [7] noted some barriers in supporting children with ASD in the Swedish preschools, barriers that had to do with implementation and the general enabling context of the preschool environment. An infrastructural disconnect between the paraprofessional and the rest of the preschool staff was noted, with the paraprofessional being excluded from meaningful planning meetings such as staff meetings, and the rest of the staff not engaging in the paraprofessionals EIBI related planning and evaluation. That led to a lack of implementation of the EIBI itself, in case of absence of the paraprofessional as well as reduced naturalistic learning opportunities involving typically developing peers, created from all the staff so that the child with ASD could engage. This outcome does not align with curriculum for the preschool LPFÖ18 (2018) which states that "The environment should be accessible for all children and inspire them to play together and to explore the world around them, and support the children's development, learning, play and communication." (p.8). Bejnö, et al. (2020) [8] mentions as well that paraprofessionals tend to feel lonely, due to lack of collaboration within the staff members along with an absence of understanding on what the paraprofessionals are working with. Based on the same study [8], an improvement in the collaboration between the paraprofessional and the preschool staff in providing an EIBI program did overall provide more support to the autistic child, support the inclusion of the paraprofessional and further improve the generalization of the child's newly gained skills in a concept apart from the interaction with the paraprofessional only.

According to the same study [7], the paraprofessional in the Swedish preschools functions as a driver for the EIBI. Paraprofessionals are the ones that push the intervention forward by organizing learning opportunities and using their competence and skills so that they can manage the high intensity of the intervention together with negotiating the inclusion of EIBI within the general preschool context, a context in which unfortunately some times they and the child become isolated and get perceived even as visitors that are under the supervision of the habilitation centers.

An interview of stakeholders that work with children with ASD describing their point of view regarding, among others, the staff's competence (Bejnö, et al. 2021) [8], reported that even though pre school principals recognize the importance of the paraprofessional's knowledge about autism and how to accommodate the autistic child's needs in the classroom, "typically, someone young, without any education, gets to do the job".

#### **9.6. The preschool environment as key feature for the development of EIBI**

Apart from the inter-organizational collaborations and the role of the pre-school teachers and paraprofessionals, another significantly important key factor for the development of EIBI came up through the literature review. The immediate preschool environment, meaning the group size and physical environment and structure is of substantial importance in supporting such a systematic and structured approach as EIBI. The most recent study (2021) of this literature review [8] touches on the importance of the preschool learning environment. The study reports that adjustments on group size by making it smaller and less noisy in order to limit the distracting stimuli help meet the needs of the autistic child. Moreover, adjustments on the communication with children with ASD by using visual support promotes a clear and structured environment that creates opportunities for the child to engage in more activities. Using other children as mediators and positive reinforcement make a great impact in mutual learning, social interaction and communication. Overall, changes in the environment helps to connect to the autistic child's individual goals that are part of the EIBI plan. The same study states also that in order to achieve sustainability in the EIBI practices, all preschool staff should be aware of those adjustments and be able to put them into practice as well.

## 10. Discussion

The purpose of this systematic literature review was to take on the attitudes of the Swedish support system in cooperation with the Swedish preschools regarding the implementation of early intensive intervention to children with autism as well as to clarify the role of the teacher in the Swedish preschool in relation to the inclusion of students with autism in the general pre-school classroom. The studies focused on understanding the EIBI supports and barriers in the Swedish preschools, although they all focused on a different aspect within the Swedish system such as the characteristics of the preschools that provide education and care to children with ASD, inclusive education, allegiance and knowledge levels of professionals who work with children with autism, inter-organizational collaboration matters, the role of the preschool teacher and the paraprofessional and the quality of EIBI provided in the Swedish preschools.

From the results of this systematic literature review appears that there is an acute need among educational staff for an increased theoretical and practical knowledge about neurodevelopmental conditions and ASD. That goal can be reached through a modified Swedish higher education program for preschool teachers, as well as paraprofessionals in order to decrease the developmental gap between autistic children and typically developing peers. Other than that, the responsibilities of the preschool teachers and the paraprofessionals working on preschool settings with children with ASD need to be more clear and definite and the support from the habilitation centers to be more substantial, including on-site practical examples and principles adjusted in the daily routine of a child with autism in preschool settings. Supervision of the preschool staff from the habilitation center and inclusion of other parties has been proven to be beneficial in providing adequate support to children in need. Besides that, by increasing the knowledge levels about ASD and EIBI on staff, will lead to a more inclusive environment for the paraprofessional and the child itself, who have been until lately pushed aside and encountered as parties outside the preschool body and are under the aegis of the habitation centers.

Moreover, more insight needs to be given into what exactly happens in the Swedish preschools in terms of early intervention so that its quality can be determined and maintained. More insight can be given through follow ups and evaluation processes with all coordinators of the intervention. In addition, in order for the EIBI quality to maintain,



more people rather than the paraprofessionals need to be actively engaged with the child with ASD. For that to happen, there is a need for a mutual agreement on a concrete plan between the preschool staff as well as participation of more staff on habilitation meetings. The obligation is on all parties, the habilitation centers need to be more engaged on the practical process and provide more guidance on the preschool staff, the teachers and paraprofessionals need to adapt the habilitation center's input and modify the preschool teaching environment having in mind on the needs of children with ASD within the terms of inclusive education. As it occurs, the importance and responsibility of the preschool principal to hire a well trained and educated paraprofessional on the role of the child's assistant is unquestionable. An educated professional on the subject of special needs and principals of EIBI results on higher levels of allegiance towards the intervention itself, better quality of the intervention and increased sustainability.

In terms of the Swedish support system, more focus need to be put on establishing more requirements for professionals who work with children with ASD. Sweden needs to feel the necessity to have an international quality assurance, a coursework meeting the BCBA (Board Certified Behavior Analysts) or BCaBA (Board Certified Assistant Behavior Analyst) and RBT (Registered Behavior Technician) standards. Specifically, more universities need to recognize the classification system by the Behavior Analyst Certification Board (BACB; <https://bacb.com/>) and provide certification to preschool teachers on a degree level. As a result of that, the preschool teachers will be way more informed about ASD and EIBI and will be able to provide better conditions during the early intervention programs, such as follow the recommended intensity of it and other aspects that need justification within the classroom.

### **10.1. Future research**

Providing early intensive behavioral intervention in preschool aged children with an ASD in Sweden is a widely discussed area in the academic community. The need of further research is vital to investigate the infrastructure and groundwork that the Swedish system in collaboration with the preschools use in order to provide EIBI and other early intervention services to children with ASD. Larger scale studies that investigate the barriers and limits on the current situation are important, but the most beneficial would be to take the results of the current studies and start making changes on different areas. Future research is

needed for example to focus on creating a theoretical framework and a mutual agreement that some control preschools and habilitation centers will include in their work in providing early intervention for children with need. That theoretical framework could for example specify to some extent the preschool staff's responsibilities, the paraprofessional's responsibilities and the habilitation responsibilities, all based on the current research, in an effort to make things clear-cut so that everyone would now exactly how to follow up with the EIBI standards. Other than that, an effort to provide more regularly an on-site guidance to the preschool staff and paraprofessionals from the habilitation centers and its long term effects can be examined. A combination of different practical measures should be applied to support the implementation of a quality enhanced early intervention and a more inclusive environment for the children with ASD within the Swedish preschool system.

The findings described in this systematic literature review add to literature just like Lise Roll-Petersson, Ingrid Olsson, Shahla Ala'i-Rosales (2016) study, that examines the supports and barriers on implementing Early intensive Behavioral Interventions in the Swedish preschools.

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