

Young Children with Autism in a Multiethnic Immigrant Population

Prevalence, Feeding Disorders, Early Detection, and Intervention

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UNIVERSITY OF GOTHENBURG

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ABSTRACT

Background: Autism is a neurodevelopmental condition characterized by a pattern of major impairments in social communication and behavioural/sensory problems, with high rates of coexisting neurodevelopmental and medical conditions. Over the past decade, there has been a documented rise in the registered prevalence of autism worldwide. Children born to immigrant parents may face an increased risk of autism. Several studies tend to suggest that they are often diagnosed with autism relatively late, potentially depriving them of important early interventions.

Aims: The studies in this thesis were performed in a multiethnic immigrant area in Gothenburg, Sweden, and had the following primary objectives (1) examine autism prevalence and risk factors, (2) describe clinical characteristics of autism, including feeding problems, (3) explore psychometric properties of the instrument Joint Attention Observation Schedule Preschool (JA-OBS preschool) in children with suspected autism, and (4) describe an intervention program based on the Early Start Denver Model (ESDM) for young children with autism in a preschool setting and capture the experiences and perspectives of the preschool staff involved in the implementation of this program.

Methods: Data were collected from a prospective longitudinal study of 46 preschool-aged children diagnosed with DSM-5 autism living in a multiethnic immigrant population area. Within this community, a local multidisciplinary team was established, focusing on diagnosis and treatment of early neurodevelopmental problems in children. All 46 children underwent thorough assessments and interventions from this team. Medical records from the Child Health Centre and comprehensive neuropsychiatric assessments were used. Data encompassed the period from pre- and perinatal stages up to the child's sixth year of age. Semi-structured interviews were conducted with 15 preschool staff members working within the area.

Results: The registered prevalence for autism in the area was 3.7%. Notably, a range of risk factors, including both genetic and non-genetic factors, were identified. A significant proportion of the children with autism experienced feeding problems (76.1%), with Avoidant/Restrictive Food Intake Disorder (ARFID) noted in 28.3% of cases. Early onset age and heterogeneity of feeding problems were highlighted. The internal consistency reliability of the JA-OBS Preschool was estimated at 0.8 (Cronbach's alpha) and percent agreement across raters ranged from 76.9% to 100%. Central components of the intervention program, grounded in the ESDM framework, were emphasised by the preschool staff. These encompassed contextual prerequisites, such as the preschool staff's participation in intervention program fostered by the local environment and features linked to the ESDM methodology. The preschool staff's experiences indicated that the implementation of ESDM significantly enriched the learning experiences of children with autism, their parents, fellow peers within the preschool, as well as the staff members themselves.

Conclusions: A high prevalence of autism among children within this immigrant population was found. Multiple associated factors for autism were documented, along with substantial individual needs of both the children and their families. This encompassed very high rates of early feeding problems and ARFID. The results underscore the imperative to develop multidisciplinary models in healthcare that increase accessibility to services for children with autism in immigrant communities. In that effort, the multidisciplinary team exemplifies how multi-faceted approaches can address immigrant families' many needs and support health equity. Preschools may hold significant potential for the early identification of autism indicators. The intervention program based on the ESDM presents a promising model for young children with autism in the multiethnic immigrant setting.

Keywords: autism, young children, immigrant population, prevalence, feeding disorders, ARFID, early detection, early intervention, Early Start Denver Model

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SAMMANFATTNING PÅ SVENSKA

Under de senaste 30 åren har antalet registrerade autismdiagnoser ökat och förekomsten av diagnostiserad autism är mellan 1–1,5%. Studier talar för att autism är vanligare hos barn till utlandsfödda föräldrar samt att den gruppen barn diagnostiseras senare än sina jämnåriga kamrater och därmed riskerar att missa viktiga tidiga insatser.

Autism innebär stora begränsningar inom två områden, nämligen social kommunikation och beteende/intressen samt sensorik. Inom social kommunikation handlar det om brister i förmågan till social ömsesidighet och kommunikation samt förmågan att utveckla och förstå sociala relationer. Barn med autism fastnar ofta i upprepat beteende, vill ha saker på sitt sätt och upplever sinnesintryck på ett annorlunda sätt. Barn med autism har nästan alltid andra samtidiga utvecklingsneurologiska problem, till exempel språk- och talproblem, motoriska avvikelser, mat- och sömnproblem och/eller intellektuell funktionsnedsättning. Även olika medicinska tillstånd, såsom cerebral pares (CP) eller epilepsi, är vanligare hos barn med autism jämfört med barn utan autism. Bakgrunden till autism är ännu inte helt klargjord, men i flertalet fall är genetiska faktorer avgörande i uppkomsten. Andra faktorer som är av betydelse är tidiga miljöfaktorer, till exempel komplikationer under graviditet och förlossning samt tidig exponering för miljögifter. Forskning de senaste åren lyfter även fram betydelsen av epigenetiska faktorer.

Forskning har visat att det är viktigt att tidigt upptäcka symtom på autism. Tidiga tecken på autism kan vara avvikelser i barnets rörelsemönster, annorlunda reaktioner på sinnesintryck och brister i förmågan till delad uppmärksamhet. Symtomen kan uppmärksammas redan under första till andra levnadsåret och hos en del barn märks en avplaning och/eller tillbakagång i utveckling av kontakt och kommunikation. Screening, exempelvis på barnavårdscentralen (BVC) kan underlätta tidig upptäckt av autismsymtom, i Göteborg screenas alla 2,5 åriga barn. Screeningen består av ett frågeformulär riktat till barnets föräldrar (Modified Checklist for Autism in Toddlers, Revised, with Follow-Up) och observation av barnet utförd av BVC-sköterskan (Joint Attention Observation Schedule, JA-OBS).

Det är viktigt med tidiga insatser riktade till barnet med autism och dess föräldrar. Det finns olika insatsmodeller och forskning ger starkt stöd för naturalistiska insatser för de yngsta barnen. Insatserna ges i barnets dagliga aktiviteter med fokus på inläring av grundläggande sociala färdigheter, till exempel delad uppmärksamhet och imitation. Early Start Denver Modell (ESDM) tillhör de naturalistiska insatsmodellerna. Föräldrarna guidas att skapa tillfällen för samspel, kommunikation och lek i barnets vardag med utgångspunkt från den

målsättning som skapas tillsammans med behandlaren. Det finns internationella studier som utvärderat ESDM i förskola med lovande resultat.

Studierna i föreliggande avhandling har utförts i ett område med en mycket hög andel invånare med utländsk bakgrund, där arbetslösheten är högre och medelinkomsten är lägre jämfört med övriga Göteborg. Sedan 2013 finns ett multiprofessionellt småbarnsteam i studieområdet, som arbetar med att utreda och ge insatser för små barn med misstänkt autism och/eller andra utvecklingsneurologiska svårigheter. Teamets målsättning är att öka tillgängligheten till vård och föräldrarnas möjlighet till delaktighet i insatserna. Den forskning som presenteras här har sitt ursprung i det kliniska arbetet i småbarnsteamet.

Den första studien avsåg att undersöka förekomsten av autism hos 2–5 år gamla barn i studieområdet och möjliga riskfaktorer för autism. Journaler från BVC och från den fördjupade utredningen i ovan nämnda team granskades. Studien inkluderade 902 barn, varav 3,7% (33 barn) uppfyllde kriterierna för autism. Vid analysen framkom både genetiska och andra riskfaktorer för autism. Resultaten underströk vikten av att öka sjukvårdens tillgänglighet för att möta de individuella behoven som finns i populationer med en hög andel av utlandsfödda.

Den andra studie fokuserade på uppfödningssproblem hos barn med autism. Studien inkluderade 46 barn med autism och data inhämtades från deras journaler. En stor andel av barnen (76,1%) hade någon form av uppfödningssproblem. Ungefär hälften av barnen hade svårare och mer ihållande uppfödningssproblem och 28,3% hade svårigheter förenliga med diagnosen undvikande/restriktiv ätstörning (ARFID). För majoriteten av barnen i ARFID-gruppen fortsatte problemen under förskoleåren. Vikten av att professionella i vården är uppmärksamma på både tidiga autismsymtom och uppfödningssproblem vid mötet med små barn betonades.

I den tredje studien studerades instrumentet, Joint Attention Observation Schedule Preschool (JA-OBS Preschool), för tidig upptäckt av autism i förskolan. JA-OBS Preschool avser att fånga brister i delad uppmärksamhet och andra svårigheter i social kommunikation. Studien inkluderade 46 barn med misstänkt autism som bedömdes med instrumentet. Studien avsåg att undersöka om JA-OBS Preschool kunde fånga symtom på autism i förskolan och om två olika bedömare skattade svårigheterna på liknande sätt. Symtom på autism kunde med hjälp av JA-OBS Preschool identifieras i förskolemiljön och det fanns en samstämmighet mellan de två bedömarna. I studien ingick endast en liten grupp barn och alla barnen hade misstänkt autism, vilket gör att fler studier behöver göras innan det går att veta om instrumentet är användbart i förskolan för att identifiera tidiga tecken på

autism. Dock verkar instrumentet vara lovande och förskolan framhålls som möjlig arena att identifiera tidiga autismsymtom.

Den fjärde studien var en intervjustudie, där förskolepersonal i studieområdet intervjuades om sina erfarenheter av att arbeta med ett insatsprogram baserat på ESDM. För att kunna arbeta med insatsprogrammet beskrev de femton deltagarna att vissa grundläggande förutsättningar krävdes. De talade om kontextuella förutsättningar, såsom småbarnsteamets lokala placering i stadsdelen och ESDM som metod. Aspekter av ESDM som lyftes fram var den gemensamma målsättningen och nätverksmötena. Vidare upplevde personalen att implementeringen av ESDM i förskolan hade en positiv påverkan på inlärningsmiljön för barnen med autism och även för de andra barnen. Samverkan med föräldrarna upplevades förbättrad och personalen fick ökad kunskap om autism och redskap för hur de kunde arbeta med barnen med autism i förskolan. Insatsprogrammet baserat på ESDM verkar vara en lovande modell för små barn med autism i området med många immigranter och låg socioekonomisk status.

LIST OF PAPERS

This thesis is based on the following studies, referred to in the text by their Roman numerals.

- I. Linnsand P, Gillberg C, Nilsson Å, Hagberg B, Nygren G. A High Prevalence of Autism Spectrum Disorder in Preschool Children in an Immigrant, Multiethnic Population in Sweden: Challenges for Health Care
Journal of Autism and Developmental Disorders. 2020; 51:538-549
- II. Nygren G, Linnsand P, Hermansson J, Dinkler L, Johansson M, Gillberg C. Feeding Problems Including Avoidant Restrictive Food Intake Disorder in Young Children with Autism Spectrum Disorder in a Multiethnic Population
Frontiers in Pediatrics. 2021; 9:780680
- III. Linnsand P, Hermansson J, Gillberg C, Nygren G. A Feasibility Study of a New Instrument for Detection of Autism Signs in Preschool Settings. Psychometric Properties of the Joint Attention Observation Schedule Preschool (JA-OBS preschool)
Frontiers in Child and Adolescent Psychiatry. 2022; 1:1061451
- IV. Linnsand P, Nygren G, Hermansson J, Gillberg C, Carlsson E. Integrating an Early Start Denver Model Program into Swedish Preschools for Young Children with Autism in a Multiethnic Immigrant Setting
In manuscript

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ABBREVIATIONS

ABA	Applied Behavior Analysis
ADHD	Attention-Deficit/ Hyperactivity Disorder
ADOS	Autism Diagnostic Observation Schedule
ARFID	Avoidant/Restrictive Food Intake Disorder
AIF	Average Intellectual Functioning
BIF	Borderline Intellectual Functioning
BMI	Body Mass Index
CHC	Child Health Centre
CHAT	Checklist for Autism in Toddlers
CP	Cerebral Pares
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
EIBIs	Early Intensive Behavioral Interventions
EDSM	Early Start Denver Model
ESSENCE	Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations
ESSENCE-Q	Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations-Questionnaire
G-ESDM	Group-based Early Start Denver Model
HDI	Human Developmental Index
ID	Intellectual Disability
ICD-11	International Classification of Diseases, 11 th Revision
IQ/DQ	Intellectual Quotient/Developmental Quotient
JA-OBS	Joint Attention Observation Schedule
JA-OBS Preschool	Joint Attention Observation Schedule Preschool
M-CHAT	Modified Checklist for Autism in Toddlers
M-CHAT-R/F	Modified Checklist for Autism in Toddlers, Revised, with Follow-Up
NDBIs	Naturalistic Developmental Behavioral Interventions
NDDs	Neurodevelopmental Disorders
RP	Regulatory Problems
SACS	Social Attention and Communication Surveillance
SCQ	Social Communication Questionnaire
SD	Standard Deviation
SES	Socioeconomic Status
SNP array	Single Nucleotide Polymorphism array
STAT	Screening Tool for Autism in Two-Years-Olds
VABS	Vineland Adaptive Behavior Scale
WHO	World Health Organization
WPPSI	Wechsler Preschool and Primary Scale of Intelligence

1 INTRODUCTION

1.1 DEFINITION OF AUTISM

Autism spectrum disorder (hereafter referred to as autism) is conceptualized as a neurodevelopmental disorder (NDDs) characterized by early onset in childhood and typically follows a lifelong course (Coleman and Gillberg 2012). The social, communication, and behavioural/sensory difficulties may lead to functional impairments in social, school, and work performance for the individual, as well as present multiple challenges for their families (Lai et al. 2014). In the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), autism includes deficits within two domains: a) social communication and interaction and b) restricted, repetitive patterns of behaviour, interests, and/or activities, including abnormal sensory processing. Autism can be diagnosed when an individual exhibits all three symptoms within the social communication domain along with a minimum of two symptoms pertaining to restricted interests/repetitive behavior/sensory problems (American Psychiatric Association 2013). To account for individual variation with an autism diagnosis, the DSM-5 provides core symptom domain severity levels, which are determined by the level of support needed for personal functioning. These are categorized as: requiring support (level 1), requiring substantial support (level 2), and requiring very substantial support (level 3). Similarly, the International Classification of Diseases 11th Revision (ICD-11) involves a dyad symptom model, where it consolidates communication and social symptoms into one domain, while placing restricted and repetitive interest/behaviour into another (World Health Organization 2019).

1.2 EPIDEMIOLOGY

1.2.1 PREVALENCE OF AUTISM

Since the early 1990s, the reported prevalence has increased from around 0.1% to 1-1.5%. Several contributing factors have been identified, including diagnostic expansion and substitution, better reporting, heightened knowledge and awareness regarding autism, and increased access to assessment services (Arvidsson et al. 2018; Atladottir et al. 2015; Coo et al. 2008; Gillberg and Wing 1999; Myers et al. 2019; Taylor et al. 2020). Environmental factors, such as infections, immunity, and exposure to environmental toxicants, have been posited to play a role in the increasing prevalence (Cheng et al. 2019; Hertz-Picciotto et al. 2018). Nevertheless, a Swedish study has demonstrated that the significance of environmental factors associated with autism has not heightened, over time

rendering them unlikely to account for the surge in prevalence (Taylor et al. 2020). However, it is important to acknowledge that the prevalence is subject to influence by geographic, ethnic, and socioeconomic factors, for example, studies from Africa and the Middle Eastern region are underrepresented (Elsabbagh et al. 2012; Zeidan et al. 2022).

A review study from 2022 estimates that approximately 1% of children worldwide receive an autism diagnosis, yet the figures diverge considerably (Zeidan et al. 2022). With a prevalence of one in 59 children aged 4 years (Maenner et al. 2021), autism bears one of the most substantial burdens among mental disorders afflicting children globally (Baxter et al. 2015). Notably, autism manifests more often in males with a male-to-female ratio from 4:1-3:1, although it is conceivable that autism in females may be subject to underdiagnosis (Lai and Szatmari 2020; Loomes et al. 2017; Wood-Downie et al. 2021). Furthermore, a higher prevalence of autism has also been reported in migrant populations (Crafa and Warfa 2015; Gao et al. 2022; Gillberg et al. 1987).

1.2.2 ETIOLOGY AND BACKGROUNDS FACTORS

The etiology of autism is complex and heterogeneous (Coleman and Gillberg 2012). The precise origins underlying this atypical neurodevelopmental condition remain poorly understood, however interplay of genetic, non-genetic, and epigenetic factors may contribute to its manifestation. Twin and family studies has demonstrated a high heritability (Sandin et al. 2017; Sandin et al. 2014; Taylor et al. 2020), with both common and rare genetic variants contributing to the observed phenotypes (Masini et al. 2020). Further, Taylor et al. (2020) found that the heritability of autism diagnoses in the Swedish Twin Registry ranged from 88% to 97%. Moreover, the recurrence risk for younger siblings of children with autism range from 7% to 19% (Grønberg et al. 2013; Ozonoff et al. 2011), versus 1-1.5% in the general population. Ozonoff et al. (2011) identified that male gender and the presence of more than one older sibling with autism as significant predictors of autism outcome. Additionally, recurrence risk varies depending on the degree of genetic relatedness. A Swedish study demonstrated a tenfold increase in relative risk when a full sibling was affected by autism, compared with a twofold increase if a cousin carries the diagnosis (Sandin et al. 2014).

Epigenetic changes have been associated with autism. Epigenetic markers, including biochemical modification of DNA or histones, affect gene expressions without altering the DNA sequence. Within the typical development of the nervous system, epigenetic mechanisms are thought to be critical. Any disruption or alteration in this process can give rise to different NDDs, including autism (Rangasamy et al. 2013). For instance, it has been proposed that some environmental factors, including folate and vitamin D insufficiency during

pregnancy, may enhance the risk of a gene mutation, which, in turn, can lead to a heightened autism risk (Kinney et al. 2010; Lintas 2019).

Moreover, a diverse array of environmental risk factors has been proposed as potential contributors to the neurodevelopmental patterns in autism. Around 40-50% of the variability in autism susceptibility may be partly attributed to environmental factors, including parental conditions as well as pre- and perinatal factors (Bolte et al. 2018; Masini et al. 2020; Modabbernia et al. 2017). In a systematic review, Carlsson et al. (2021) found that advanced paternal age, low birth weight, congenital defects, perinatal hypoxia, and perinatal respiratory stress were associated with autism.

Several studies have indicated an association between migration, ethnic minority status, and the risk of autism, with a particular emphasis on maternal migration (Abdullahi et al. 2019; Crafa and Warfa 2015; Schmengler et al. 2021). In contrast, the association between parental socioeconomic status (SES) and autism remains contentious. For instance, studies in the United States have reported that the prevalence of autism heightened with increasing parental SES, whereas in European countries, no such association was identified. Conversely, in studies conducted in Europe, researchers have observed an inverse relationship, linking lower SES with higher autism risk (Delobel-Ayoub et al. 2015; Durkin et al. 2017; Durkin et al. 2010; Lehti et al. 2015; Rai et al. 2012b). Rai et al. (2012b) have suggested that the conflicting results may reflect differences in the availability and affordability of healthcare services.

The prevailing focus in research on autism has predominantly centred on genetic and environmental risks. However, there is increasing research interest in the role of potentially protective factors, such as prenatal vitamin supplementation, fatty acids including the omega-3 group, as well as probiotic supplementation during pregnancy (Hoxha et al. 2021; Martins et al. 2020; Slattery et al. 2016). Consequently, more research is essential to gain a comprehensive understanding of the contributory role of the potential protective factors in mitigating autism.

1.2.3 DIAGNOSIS OF AUTISM AMONG CHILDREN BORN TO IMMIGRANTS

In several studies, the risk of autism has been shown to be higher among children of immigrants, especially for autism with comorbid Intellectual Disability (ID) (Abdullahi et al. 2019; Barnevik-Olsson et al. 2010; Crafa and Warfa 2015; Gao et al. 2022; Gillberg et al. 1995; Morinaga et al. 2021; Schmengler et al. 2021). Nevertheless, the precise impact of migration on autism remains unclear. Several explanations have been proposed for this increased risk of autism within immigrant populations, including viral infections in pregnancy, nutrition, and

vitamin insufficiency (Gillberg et al. 1987; Lee et al. 2021; Schmidt et al. 2012), stress and trauma from migration (Augereau et al. 2020; Rai et al. 2012a), the timing of migration or pregnancy (Hansen et al. 2023; Magnusson et al. 2012), and other sociodemographic factors (Lehti et al. 2015; Rai et al. 2012b).

The influence of migration status on autism manifests uniquely depending on various factors such as parental migration history, generation of migration and both the origin and destination of the migrant. Augereau et al. (2020) have found that pre-migration social adversity based on Human Developmental Index (HDI) was linked to autism, whereas migration experience (migratory trip and post-migration experience), showed no significant association. Magnusson et al. (2012) have observed a higher risk of autism in cases where parents had migrated, particularly from countries characterized with low HDI. Furthermore, other studies examining the associations between migration and autism focused on aboriginal countries with comparable low HDI, even if HDI values are not explicitly described (Becerra et al. 2014; Keen et al. 2010).

Some researchers have hypothesized that epigenetic changes within migratory communities increase autism risk (Crafa and Warfa 2015). Augereau et al. (2020) proposed that social adversity experienced in the native country may give rise to pre-migration stress, including psychological and biological stress. When combined with the potential trauma associated with the migratory journey and post-migration experience, the pre-migration stress may lead to alternations in gene expression through epigenetic mechanisms, thereby potentially influencing the development of autism (Augereau et al. 2020; Cao-Lei et al. 2020).

Nevertheless, it is worth noting that some studies have also reported contrasting findings, indicating either a reduced prevalence and lower risk of autism among children of immigrant parents or no discernible difference in risk compared to children of non-immigrant parents (Augereau et al. 2020; Singh et al. 2013).

1.2.4 COMORBIDITIES AND THE CONCEPT OF ESSENCE

As a group, children with autism are at high risk of having comorbid NDDs and medical conditions (Fennell and Gillberg 2023; Gurney et al. 2006; Lai et al. 2019; Mutluer et al. 2022). Gillberg (2010) introduced the acronym Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations (ESSENCE) with a view to put a focus on the almost pervasive overlap of symptoms and coexisting NDDs in early childhood. Coexisting neurodevelopmental and psychiatric conditions are highly prevalent in children with autism. These include sleep and feeding disorders, ID, Attention/Deficit/Hyperactivity Disorder (ADHD), and language disorders (Fennell and Gillberg 2023; Gillberg and Billstedt 2000; Lai et al. 2019; Mutluer et al. 2022).

Soke et al. (2018) have reported that nearly all 4-year-old children with autism had at least one concurrent neurodevelopmental condition, with 53% exhibiting four or more co-occurring conditions/symptoms. In a Swedish study of 9-year-old children with autism, Lundstrom et al. (2015) found that 50% of those had four or more coexisting disorders, while just 4% had no concomitant disorder. According to a review of population-based studies, 18.4% of the children with autism also had ADHD, and 21.4% had comorbid ID (Mutluer et al. 2022). Among Italian preschool children with autism, 20.4% of the children had comorbid ADHD (Fucà et al. 2023). Maenner et al. (2021) reported that in their group of 4-year-old children with autism had 51.5% ID.

Sleep problems are frequent in children with autism. 60–86% of them experience some form of sleep disturbance, in contrast to 9-50% of children without autism (Martin et al. 2021; Posar and Visconti 2020; Souders et al. 2017). These sleeping problems exert a negative impact on cognitive and adaptive functions, potentially exacerbating aggression, irritability, inattention, and hyperactivity in children with autism. Further, they can also be linked to the severity of the core symptoms of autism, including challenges in social cognition and communication and hypersensitivity to the environment (Cohen et al. 2017; Lindor et al. 2019; Whelan et al. 2022). Disturbed sleep in a child also negatively affects the whole family's health and well-being, e.g. quality of life and maternal mental health (Liu et al. 2021; Martin et al. 2021).

Medical comorbidities in children with autism manifest across several areas, e.g. neurology, immunology, and gastroenterology (Muskens et al. 2017). In a systematic review, Pan et al. (2021) have observed a heightened incidence of neurological disorders, including epilepsy, macrocephaly, hydrocephalus, cerebral palsy, migraine/headache, and inborn nervous system abnormalities, in individuals with autism. Within the realm of immunology, most studies have centered on allergic and autoimmune diseases. While results are conflicting, some studies have unveiled an association between autism and allergies, alongside autism and autoimmune diseases (Tonacci et al. 2017; Zerbo et al. 2015). There is some evidence that gastrointestinal symptoms, including constipation, diarrhea, and abdominal pain, are more common in children with autism (Leader et al. 2022; Wang et al. 2022a).

1.2.5 EATING AND FEEDING PROBLEMS INCLUDING ARFID IN AUTISM

The prevalence of feeding problems among children with autism has been reported to range between 50 to 90% (Sharp et al. 2013). The feeding problems are characterized by limited food repertoire, food refusal, and rigid behaviours

surrounding meals (Marí-Bauset et al. 2014; Schreck et al. 2004; Thullen and Bonsall 2017). For example, Mayes and Zickgraf (2019) showed that atypical eating behaviours, including limited food preferences, texture hypersensitivity, and brand-specific preferences, were 15 times more common in children with autism than in children without autism. Sensory sensitivities in children with autism may contribute to the acceptance or refusal of food based on its texture, temperature, taste, colour, and/or appearance, thereby contributing to a restrictive diet (Baraskewich et al. 2021; Bourne et al. 2022; Mayes and Zickgraf 2019). Moreover, restrictive and repetitive behaviours have been found to correlate with food selectivity in autism (Mayes and Zickgraf 2019; Prosperi et al. 2017). Significant food selectivity is associated with a greater risk of poor health, such as low weight or significant weight loss and/or nutritional deficiencies, as well as difficult mealtime behaviour and heightened parental stress (Bourne et al. 2022; Sharp et al. 2013).

Avoidant/restrictive food intake disorder (ARFID) was first described as a diagnostic category in DSM-5 (American Psychiatric Association 2013) and, more recently, in the ICD-11 (World Health Organization 2019). The disorder is characterized by the avoidance of specific foods, resulting in a limited range of food the individual will eat and/or restricted food intake leading to nutritional or energy deficits (American Psychiatric Association 2013). While the prevalence of ARFID in the general population stays unclear, it is estimated to fall within the range of 0.5%-5% (Chen et al. 2019; Dinkler et al. 2021; Kurz et al. 2015; Schmidt et al. 2018). ARFID appears to exhibit a high comorbidity with autism (Bourne et al. 2022; Sharp et al. 2018). Koomar et al. (2021) found that 21% of the children with autism also met criteria for ARFID.

1.3 EARLY SYMPTOMS, DIAGNOSIS, AND INTERVENTIONS IN AUTISM

1.3.1 EARLY SYMPTOMS

Studies have shown that behavioural indicators of autism may emerge during the first year of life, which may include delayed motor control, feeding and sleeping difficulties, and excessive reactivity or passivity, as well as difficulties in the core domain social communication (Estes et al. 2015b; MacDuffie et al. 2020; Ozonoff et al. 2008; Ozonoff et al. 2010; Vasilakis et al. 2022; Zwaigenbaum et al. 2019).

In infancy, eating, sleeping, and excessive crying are referred to as regulatory problems (RPs), and they are associated with an increased risk of dysregulation and subsequent developmental problems (Bedford et al. 2019; Hemmi et al. 2011; Olsen et al. 2019; Schmid et al. 2010). In a Swedish study, Barnevik Olsson et al.

(2013) have found that RPs were more common in children who later received an autism diagnosis. In a review, Vasilakis et al. (2022) found correlations between food difficulties and autism among infants aged 0-2 years, including early breastfeeding problems, food selectivity, disruptive mealtime behaviour, and food refusal. To illustrate, Provost et al. (2010) noted that parents of children with autism reported concerns regarding distinct eating behaviour from the child's first week of life (25%), with these concerns appearing to increase gradually in the first (37%) and second year (50%). Furthermore, sleep disturbances are among the first concerns parents report in young children later diagnosed with autism (Ozonoff et al. 2008). MacDuffie et al. (2020) reported that sleep onset problems were more common at 6-12 months in infants who later received an autism diagnosis compared to typically developing peers.

Additionally, studies have shown that both delayed motor development and atypical motor function, including stereotyped movements, could be discerned even prior to the emergence of deficits in social communication characteristic of autism (Posar and Visconti 2022). Also, regressive patterns have been highlighted as early behavioral signs of autism (Ozonoff and Iosif 2019; Thompson et al. 2019). Ozonoff and Iosif (2019) have proposed that regressive onset patterns emerge much more often than earlier recognized. Some prospective studies have yielded regression estimates of over 80% (Ozonoff et al. 2018; Pearson et al. 2018).

Furthermore, indications of autism within the core domain of social communication can be noticed between 6 and 12 months (Ozonoff et al. 2010). The early symptoms are manifested as, for example, reduced social engagement, delayed language development without compensatory gesturing, reduced eye contact, reduced response to name, lack of pretend play, and reduced joint attention behaviour (Ozonoff et al. 2008; Sacrey et al. 2015; Zwaigenbaum et al. 2019). Joint attention behaviour refers to the capability to synchronize simultaneous focus attention between two individuals and an object or event, facilitating a shared experience. Joint attention manifests in two types of behaviour: (a) responding to joint attention, whereby a person responds to the eye-gaze shift and/or gesture of another person by attending the object or event, and (b) initiating joint attention, whereby a person initiates the eye-gaze shift and/or gesture with the intension of sharing the experience of the object or event (Bruinsma et al. 2004; Mundy 2018; Mundy et al. 2009). In typically developing children, these behaviours emerge in the first 6 months of life and grow into complex and coordinated behaviour between 8 and 18 months of age. Challenges in joint attention constitute one of the most salient features of autism in young children (Mundy 2018). For example, Nyström et al. (2019) observed that infants subsequently diagnosed with autism exhibited marked deviations in initiating joint attention compared to their typically developing peers.

1.3.2 AUTISM SCREENING

Autism can be reliably diagnosed from 14 months of age (Hyman et al. 2020; Ozonoff et al. 2015; Pierce et al. 2019; Sanchack and Thomas 2016; Zwaigenbaum et al. 2015b), yet the median age of autism diagnosis remains over the age of four years (Baio et al. 2018). Crane et al. (2016) found a delay of three and a half years between the parents' first contact with a healthcare professional concerning their child's development and the formal autism diagnosis. A review of early detection methods for autism in primary care and community settings has demonstrated that routine screening increases the rate of referrals (Daniels et al. 2014). In the United States, standardized screening for autism symptoms has been recommended at 18 and 24 months of age within pediatric primary care (Sacrey et al. 2015; Zwaigenbaum et al. 2015b). Sanchez-Garcia et al. (2019) investigated the diagnostic accuracy in a meta-analysis and found that tools which are used in universal screening are effective in identifying autism signs at 14-36 months.

Several screening tools are available to identify early autism signs. The screening tool for autism is based on early manifestations of symptoms related to social communication but also restricted, repetitive behaviours and abnormal sensory processing. They come in various formats, such as parent-reported questionnaires, direct assessment of the child or a combination of the two (Barbaro and Halder 2016; Baron-Cohen et al. 1992; Nygren et al. 2012; Salgado-Cacho et al. 2021; Zwaigenbaum et al. 2015b).

The Modified Checklist for Autism in Toddlers (M-CHAT/M-CHAT-R/F) is the most extensively used and researched screening tool for autism. This parent-report questionnaire comprises of 20 items, and a positive outcome prompts a follow-up interview by the healthcare professionals (Robins and Dumont-Mathieu 2006; Robins et al. 2001). Robins (2008) has suggested that M-CHAT is efficacious in identifying autism in primary care. Furthermore, the M-CHAT-R/F has proven to be an effectual instrument for screening toddlers, reducing the age of autism diagnosis by 2 years compared to the United States national median age (Robins et al. 2014). The original Checklist for Autism in Toddlers (CHAT) used a combination of the parental report and clinical assessment of the child (Baron-Cohen et al. 1992). The Social Attention and Communication Surveillance (SACS) is an observation-based, early developmental surveillance tool for autism, if required, the parental or caregiver report can be administered (Barbaro et al. 2022). The Screening Tool for Autism in Two-Years-Olds (STAT) is an observations-based instrument and evaluates behaviors in the domains of play, communication, and imitation skills (Stone et al. 2004).

Our group used a combination of M-CHAT-R/F and a five-item instrument, Joint Attention Observation Schedule (JA-OBS), for clinical assessment of autism in

child healthcare. The JA-OBS includes observations of joint attention behaviours and other socio-communicative skills (Nygren et al. 2012).

Moreover, one potential setting for early detection of autism signs is preschool. Preschool may constitute a child's primary interaction with individuals beyond their immediate family, and the child dedicates numerous hours each week in this environment. Several studies have demonstrated that preschool staff can adeptly identify autism signs and other atypical traits in early development, even in socioeconomic disadvantaged and multiethnic settings (Gulsrud et al. 2019; Janvier et al. 2016; Thompson and Winsler 2018). For example, in underserved communities, Janvier et al. (2016) have found that early childcare providers can efficiently screen young children for autism within a preschool setting using M-CHAT or/and the Social Communication Questionnaire (SCQ). Furthermore, Gulsrud et al. (2019) established that the childcare setting constitutes a promising arena for screening in low-resource and ethnically diverse populations.

1.3.3 CLINICAL ASSESSMENT AND DIAGNOSIS

Ozonoff et al. (2005) have highlighted some important considerations in the diagnostic process, a) a developmental approach must be maintained, b) the assessment of the child with suspected autism should include information from multiple sources and context, and c) a multidisciplinary team is recommended. A comprehensive assessment is essential, including core autism symptomatology, cognitive level, language, adaptive behaviour, neuropsychological functions, coexisting conditions (e.g. medical conditions and other neurodevelopmental conditions), as well as overall social and specific contextual factors (Lai et al. 2014; Ozonoff et al. 2005).

1.3.4 EARLY INTERVENTION IN AUTISM

Early interventions are essential, both for treating prodromal symptoms and manifested autism (Zwaigenbaum et al. 2015a). Dawson (2008) has underscored the second year of life as a crucial period characterized by significant neural plasticity affording a greater potential to influence developmental course. Also, Ismail et al. (2017) have suggested that critical periods of brain development may present windows of opportunity for interventions. Interventions prior to the age of four have demonstrated associations with improvements across several developmental domains, such as cognition and language (Dawson et al. 2010; Fuller et al. 2020; Rogers et al. 2019).

In a review, Zwaigenbaum et al. (2015a) summarized recommendations for early intervention, a) interventions for children aged <3 years with suspected or

confirmed autism should integrate both developmental and behavioural approaches and begin as early as possible, b) active involvement of families and/or caregivers in the intervention process, c) comprehensive intervention addressing both core symptoms and related difficulties, and d) the sociocultural beliefs and socioeconomic aspects of the family should be considered in the intervention services.

A diverse array of early intervention programs caters to young children with autism, and there are numerous ways in which the interventions can be delivered. While the intervention programs are heterogeneous, most of them have a behavioural and/or educational approach (Lai et al. 2014; Zwaigenbaum et al. 2015a). For example, Early Intensive Behavioral interventions (EIBIs) are based on applied behaviour analysis (ABA) and originate from the Lovaas method (Reichow et al. 2018). The intervention is delivered in a structured context with prompt hierarchies and reinforcement schedules. Specific skills are taught in a prescribed order, for example, social, communication, cognitive, and pre-academic skills (Granpeesheh et al. 2009).

1.3.5 NATURALISTIC DEVELOPMENTAL BEHAVIORAL INTERVENTIONS

Naturalistic Developmental Behavioral Interventions (NDBIs) constitute a group of interventions that use strategies from ABA but also strategies retrieved from developmental science to teach developmentally appropriate skills. NDBIs are mainly focused on the needs of young children with autism (up to four years of age). The NDBIs share essential features, including focus on developmental-based learning targets and elementary social learning skills, for example joint attention and imitation. The learning context involves the child's daily interactions, experiences, and play routines within the natural environments. The interventions are highly child-directed and use techniques to promote spontaneity, initiative, and generalized skills, including incorporating family members and other caregivers in the interventions (Frost et al. 2020; Schreibman et al. 2015).

In a systematic review and meta-analysis of early interventions for children with autism, Sandbank et al. (2020) demonstrated that NDBIs had the most robust amount of evidence compared to other interventions.

1.3.6 THE EARLY START DENVER MODEL

The Early Start Denver Model (ESDM) is a NDBI developed for very young children with autism (aged 12-48 months). This is a comprehensive intervention

program focusing on autism-specific impairments spanning various developmental domains, including expressive and receptive language, social interaction, and play skills. ESDM incorporates principles of developmental science, applied behaviour analysis, and social-affective neuroscience to support learning and development in young children with autism. The caregivers undergo training in basic ESDM strategies, thus facilitating implementation across the daily activities built on the child's spontaneous interest and motivation. (Rogers and Dawson 2010). The ESDM has been widely studied (Aaronson et al. 2022; Fuller et al. 2020; Rogers et al. 2019). A randomised control study evaluating the efficacy of the ESDM showed significant improvements in IQ, language development, social, and adaptive skills (Dawson et al. 2010), and these improvements were mostly preserved two years after entering intervention (Estes et al. 2015a). Furthermore, in a review article that included 11 high-quality randomised controlled studies, Wang et al. (2022b) found that ESDM improved autism symptoms, language, and cognition.

While the primary mode of implementation has traditionally been on an individualized basis, alternative approaches have been developed, such as group-based delivered intervention. The Group-based ESDM (G-ESDM) is delivered within group day care settings, both in inclusive and specialized environments, i.e. autism specific preschools (Masi et al. 2022; Sinai-Gavrilov et al. 2020; Vivanti et al. 2017; Vivanti et al. 2014a). Vivanti et al. (2019) have found that G-ESDM improved the child's spontaneous vocalisation, social interaction, imitation, verbal cognition, adaptive behaviour, and autism symptoms, irrespective of the intervention setting. Further, Vivanti et al. (2022) have studied different factors associated with social communicative outcomes for children receiving G-ESDM in inclusive versus autism-specific classrooms. Both groups presented comparable results at group mean across communication and social behaviour measures. However, children with higher social interest and nonverbal cognitive skills might benefit more from the inclusive educational setting.

1.4 FAMILIES OF CHILDREN WITH AUTISM

A review by Bonis (2016), reported that parents of children with autism experienced raised stress levels compared to parents of typically developing children. This stress was found to surpass that experienced by parents of children with other disabilities. Batool and Khurshid (2015) have found that the severity of the child's disability seemed to be the most prominent risk factor for parental stress. The parental stress level seems to be more closely linked to the child's behavioural and emotional regulation difficulties than to the core autism symptomatology (Di Renzo et al. 2020). In an interview study of immigrant

families in Canada, the parents described the impact on social life, such as feelings of embarrassment concerning the child's agitated behaviour, and the emotional and physical burden, such as the pressure from the school and the healthcare (Pondé et al. 2019).

Further, social impact and stigma are commonly experienced by parents of children with autism in general, as well as among ethnic minority groups (Liao et al. 2019; Pang et al. 2023). In case of Hispanic parents, Martinez and Turnage (2022) have highlighted that addressing autism stigma through culturally sensitive social support interventions may be an important way to reduce parenting stress.

Additionally, studies have reported barriers to timely access healthcare system, such as interventions, among immigrants (Schmengler et al. 2021; Sritharan and Koola 2019). For instance, Amant et al. (2018) have found that children whose parents did not have English as their primary language received significantly fewer hours of services provided by their state disability program. Sritharan and Koola (2019) underscored that culturally sensitive program may address the barriers and provide equal healthcare service for families and children with immigrant backgrounds.

2 AIMS OF THE THESIS

The thesis is based on four studies that had the following specific aims:

- I Examine the prevalence, risk factors and needs in preschool children with autism living in a multiethnic immigrant population district of Gothenburg
- II Study the prevalence and characteristics of feeding problems including ARFID in preschool children with autism
- III Explore the psychometric properties of a new instrument, the JA-OBS Preschool, in children with suspected autism
- IV Describe an intervention program based on the ESDM in a multiethnic immigrant setting, and capture the preschool staff's experiences of working with this program

3 PARTICIPANTS AND METHODS

An overview of the study designs and outcomes is provided in Table 1.

Table 1. Thesis overview including study groups and methods

	Study I	Study II	Study III	Study IV
	”Prevalance”	”Feeding”	”JA-OBS Preschool”	”ESDM in preschools”
Research topic	The prevalence of autism in preschool children in an immigrant population	Feeding problems, including ARFID, in preschool children with autism	The psychometric properties of the JA-OBS Preschool in children with suspected autism	The preschool staffs’ experiences of working with the intervention program based on the ESDM
Study design	Prospective longitudinal study	Prospective longitudinal study	Prospective longitudinal study	Qualitative explorative study
Study group	n=902 (454 males, 448 females) Children aged 2-5 years registered at the CHC in the study area on Dec 31, 2018	n=46 children diagnosed with autism (37 males, 9 females), average 38 months	n=46 children diagnosed with autism (37 males, 9 females), average 38 months	n=15 preschool staff (females only)
Data source	Medical records from the CHC and the comprehensive neuropsychiatric assessment	Medical records from the CHC and the comprehensive neuropsychiatric assessment	Medical records from the CHC and the comprehensive neuropsychiatric assessment	Interviews
Measurements	Prevalence estimates Parameters including demographics, maternal country of birth, timing of migration to Sweden, prenatal and perinatal history, heredity, genetic analyses, and results of the diagnostic assessment	ESSENCE-Q, RPs, BMI and Growth charts, medical assessments including laboratory analyses	JA-OBS, JA-OBS Preschool	

JA-OBS Preschool = Joint Attention Observation Schedule Preschool

ESDM = Early Start Denver Model

ARFID = Avoidant/Restrictive Food Intake Disorder

JA-OBS = Joint Attention Observation Schedule

CHC = Child Health Centre

ESSENCE-Q = Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations-Questionnaire

RPs = Regulatory Problems

BMI = Body Mass Index

3.1 STUDY SETTINGS

The studies were conducted in a multiethnic and socioeconomically disadvantaged area in Gothenburg, Sweden, with ~12,700 inhabitants, of whom ~1,130 were children aged 0-5 years at the end of 2022. The area has a high proportion of immigrants; 90.5% of the population has non-Swedish backgrounds¹, compared to the 38.1% citywide average in Gothenburg. The most common birth countries are Somalia (9.6%), Iraq (9.1%), and Syria (6.2%). Ill health, high unemployment, and low average income is prevalent in the study area (SCB/Gothenburg City Council 2023). Further, the area is among those identified by Swedish police as particularly vulnerable – a term denoting regions marked by a low SES where criminal activities exert a discernable impact on the local community (Polismyndigheten 2021).

3.2 THE HEALTH CARE SETTING

3.2.1 THE CHILD HEALTH CENTRE

In Sweden, nearly all children visit the local Child Health Centre (CHC) for regular check-ups. In Gothenburg, the public health services have implemented a screening program aimed at identifying early signs of autism (Central Barnhälsovård Västra Götalandsregionen 2018). At the age of 30 months, each child undergo screening through the utilization of the M-CHAT-R/F questionnaire, along with a clinical observation facilitated by the use of JA-OBS (Nygren et al. 2012; Robins et al. 2001). In the studied area, children with suspected autism and/or other NDDs are referred to the multidisciplinary team for further assessment.

3.2.2 THE LOCAL ASSESSMENT AND INTERVENTION PROGRAM IN THE STUDIED AREA

Since 2013, a dedicated local assessment and intervention program has been in operation to support families with young children affected by NDDs, particularly autism, within the study area. The multidisciplinary team provides assessment and interventions close to the family's location in cooperation with the healthcare nurse at the local CHC, the preschool staff, and other social services. The program's primary objectives are to facilitate assessment and intervention to these families locally, thereby enhancing the accessibility and continuity of healthcare services, while also encouraging active parental participation in the interventions.

¹ Individuals born abroad or born in Sweden with both parents born abroad.

For further information regarding the assessment and interventions, please refer to sections 3.7.1 and 3.7.2.

3.3 THE PRESCHOOL SETTING

In Sweden, almost all children, including those with autism, attend preschool. Among two-year-olds, 91.3% attend preschool, with 82.7% of those hailing from non-Swedish backgrounds² (Skolverket 2022). Preschool education marks the initial stage in the educational system, and it is a part of the Swedish Education Act (Skolverket 2010). The Swedish preschool curriculum encapsulates the preschool's fundamental values, goals, and guidelines. It emphasizes equality, with the onus on preschools to support children with special needs ensuring their optimal development (Skolverket 2018).

3.4 STUDY POPULATIONS

3.4.1 STUDY I

The target population comprised all children born in the geographical area from January 1, 2013, through December 31, 2016, and registered at the CHC in the study area on December 31, 2018. On the day of census, a total of 902 children (454 males, 448 females) were registered. Potential risk factors (see section 3.5.1) for autism were analysed in 31 children (23 males, 8 females). The average age for registered autism diagnosis was 36.3 months (range 22-61, SD 8.8).

3.4.2 STUDY II-III

The study group comprised 46 children (37 males, 9 females), all born between 2010-2016 and diagnosed with autism in accordance with DSM-5 criteria (American Psychiatric Association 2013). All children were registered at the CHC in the study area. The majority underwent autism screening at the age of 30 months or earlier if there was suspicion of autism.

The average age at which autism was diagnosed was 38 months (range 22-61, SD 9). Twenty-five children (54.3%) had autism level 1, and 21 (45.7%) had autism level 2. Six children (13%) had average intellectual functioning (Intelligence Quotient (IQ)/ Developmental Quotient (DQ) ≥ 85), 12 children (26.1%) had borderline intellectual functioning (IQ/DQ 70–84), and 28 children (60.9%) ID

² Children born abroad or in Sweden with both parents born abroad.

(IQ/DQ <70). All 46 children presented coexisting symptoms, other NDDs and/or other medical conditions (Table 2). All children but one, lived in the study area, and 93% of the parents had a non-Swedish background.

Table 2. Autism severity, intellectual functioning, and coexisting symptoms in children with autism (n=46)

		n (%)
Autism severity	Level 1 (mild deficits)	25 (54.3)
	Level 2 (marked deficits)	21 (45.7)
	Level 3 (severe deficits)	-
Intellectual functioning	Average (IQ/DQ ≥85)	6 (13)
	Borderline (IQ/DQ 70-84)	12 (26.1)
	ID (<70)	28 (60.9)
Coexisting symptoms, other NDDs, and/or other medical conditions		46 (100)

ID = Intellectual Disability

IQ/DQ = Intelligence Quotient/Developmental Quotient

3.4.3 STUDY IV

The study group comprised 15 preschool staff, all of whom were experienced in implementing the intervention program based on the ESDM in the study area. Six of the participants were preschool care workers³, five were preschool teachers⁴, three were principals⁵, and one was a special education teacher⁶. All participants were female. Their collective experience in the preschool setting ranged from 4-42 years (mean 20.3, SD 12.2). All participants had worked with at least two children in the intervention program (range 2-25).

3.5 DATA TYPE AND MEASURE

3.5.1 STUDY I

Study I used data extracted from each patient's medical record at the CHC and the comprehensive neuropsychiatric assessment made by the multidisciplinary team. The parameters included demographics, maternal country of birth, timing

³ Professionals with upper secondary education

⁴ Professionals with university degrees in Preschool Education

⁵ Professionals with university degrees in Preschool Education with add-on education for principals

⁶ Professionals with university degrees in Preschool Education and further education in special education

of migration to Sweden, prenatal and perinatal history, hereditary factors, genetic analyses, and results from the diagnostic assessments.

To identify potential risk factors for autism, four systematic reviews were used (Crafa and Warfa 2015; Modabbernia et al. 2017; Ng et al. 2017; Wang et al. 2017). These risk factors were divided into five domains: *geographic region of maternal birth, other prenatal risk factors, perinatal risk factors, NDDs in the family, and genetic findings/syndromes*. Additionally, data from the Swedish Medical Birth Register were used (pregnancy outcomes, which included information on preeclampsia and deliveries completed by caesarean section; Apgar score <7 after 5 min; full term pregnancy; birth before 37 weeks' gestation; low birth weight, <2500 g; small size for gestational age) (Socialstyrelsen 2020).

The maternal country of birth and the timing of migration in relation to the child's birth were recorded. The timing of migration was divided into three groups: (a) the migration occurred ≥ 1 year before the child's birth; (b) in the year before birth; (c) after birth. The maternal country of birth was also studied by level of human development (using the United Nations Development Programme HDI) (United Nations Development Programme 2019).

3.5.2 STUDY II

Study II was based on similar data as study I. Parameters recorded included demographics, prenatal and perinatal history, RPs, along with coexisting neurodevelopmental and medical conditions. Further, growth charts, body mass index (BMI), results from blood tests and other relevant medical assessments as well as required treatment approaches were included. The feeding problems were studied retrospectively from the child's first months, and were classified and diagnosed at the time of the autism diagnosis. A subsequent evaluation of the feeding problems was conducted two years after the initial autism diagnosis.

The ESSENCE Questionnaire (ESSENCE-Q) was used to delineate concurrent coexisting neurodevelopmental concerns (Gillberg 2010; Gillberg 2018; Hatakenaka et al. 2016). The ESSENCE-Q comprises 12 items: general development, motor development, sensory reactions, communication/language, activity/impulsivity, attention/concentration, social interaction, behaviour, mood, sleep, feeding, and "funny spells"/absences. The ratings were based on clinical observation of the child, coupled with a parental interview during the initial visit as a part of neuropsychiatric assessment. Responses of "Yes" (2 points), "Maybe/A little" (1 point), or "No" (0 points) were recorded for each of the 12 items (total scores range 0-24 points).

Growth charts were used with SD to assess growth over time (The Swedish Association of Local Authorities and Regions 2021).

3.5.3 STUDY III

Study III used similar data as study II and III, including outcomes from the autism screening at CHC, demographics, and results from diagnostic assessment.

In study III, the JA-OBS and the JA-OBS Preschool were used. The JA-OBS is a five-item observation of the child's capability to engage in joint attention activities (initiation and response of joint attention). The observation also involves social communication behaviours, such as the child's responsiveness to their own name and the ability to engage in pretend play (Table 3, item 1-5). Nygren et al. (2012) developed the instrument based on insights into early autism signs associated with reduced joint attention and social communication behavior. Screen positivity for joint attention problems was defined as the child failing to show two or more of the five behaviors.

The JA-OBS Preschool extends the original JA-OBS by including the initial five items, along with the addition of two supplementary items (Table 3, item 6-7). These added items focus on aspects of social communication that can be observed in a preschool environment. Based on previous research of JA-OBS and drawing from clinical experience related to the JA-OBS Preschool, screen positivity on the JA-OBS Preschool was defined as failure on two or more of the seven items (Nygren et al. 2012).

Table 3. JA-OBS (item 1–5) and JA-OBS preschool (item 1–7)

Does the child ...

1. react to own name (turns to person addressing the child)?
 2. try to establish eye contact with you?
 3. gaze at something that you point to further away in the room?
 4. use her/his index-finger to point at something (e.g., in a book)?
 5. interact with you or parent in pretend play (e.g., during feeding a doll, or putting the doll to bed; does the child use eye contact to monitor that you are watching)?
 6. show interest in other children?
 7. take some initiative to contact others for play, to show something, to tell something, not just because others are looking for contact?
-

3.5.4 STUDY IV

Study IV was a qualitative explorative study with semi-structured focus group interviews conducted with a view to gaining insights into the experiences of preschool staff working with the intervention program based on the ESDM.

3.6 DEFINITIONS

3.6.1 STUDY II

RPs were defined as persistent problems with eating, sleeping, and/or excessive crying after three months of age and regarded as serious problems by the caregiver and/or the clinician. Based on age of onset, the symptoms are divided into three groups: very early onset (0-3 months), early onset (4-12 months), and late onset (13-18 months).

The category of *feeding problems* was defined as any kind of problem with eating and/or feeding. Feeding problems were divided into *feeding difficulties* and *feeding disorders*. *Feeding difficulties* were used when there was some parental concern regarding the child's eating behaviour, i.e. some selectivity, mealtime behaviour problems, or other transient problems that do not necessitate treatment efforts from healthcare. *Feeding disorders*, on the other hand, were characterized by concerns related to compromised growth and/or nutritional deficiency and/or difficulties during mealtimes persisting for more than three months and requiring special efforts from healthcare. The onset age for feeding problems was divided into four groups: 0-5 months, 6-12 months, 13-24 months, and >24 months. To retrospectively establish an ARFID diagnosis, the DSM-5 criteria were used. At least one criterion, A1-A3, had to be fulfilled (only A4 was not sufficient), as well as criteria B, C, and D (American Psychiatric Association 2013). For this study, operationalization of the DSM-5 criteria A1-A4 was developed (Table 4). Feeding disorders that did not meet the criteria for ARFID were referred to as other feeding disorders. Furthermore, the suggested criteria for Pediatric Feeding Disorder by Goday et al. (2019) were also used in this study.

Table 4. The DSM-5 ARFID criteria A1-4 and the definitions of the criteria used in the present study

Criteria	The DSM-5 ARFID criteria	The definition of the criteria used in the present study.
A1	Significant weight loss (or failure to achieve expected weight gain or faltering growth in children)	BMI \leq -2 SD for more than three months or growth delay defined as a deflection of >0.5 SD in weight and height per year in growth charts or a deflection of >1 SD at any time at the age of 2-6 years.
A2	Significant nutritional deficiency	Deviations in laboratory data (iron deficiency, S-Fe $< \mu\text{g}15$ and/or low 25 (O.H.) D-Vitamin $<30\text{nmol/}$ in need of treatment and/or insufficient nutritional intake according to diarized daily logs (according to dietician assessment).
A3	Dependence on enteral feeding or oral nutritional supplements	Dependence on enteral feeding or oral nutritional supplements after dietician assessment ≥ 1 supplement drink (300-400 kcal) daily.
A4	Marked interference with psychosocial functioning	Inability to attend preschool or ability to attend only for 3 hours per day due to inability to manage the eating situation at preschool and/or marked fatigue/irritability reported due to nutritional deficiency at preschool and/or at home.

3.7 PROCEDURES

3.7.1 THE COMPREHENSIVE NEUROPSYCHIATRIC ASSESSMENT

The neuropsychiatric assessment team consisted of a pediatrician/child psychiatrist, a developmental psychologist, a special education teacher, a speech and language pathologist, a child specialist nurse, and a social worker.

The neuropsychiatric assessment included: 1) physical developmental examination, hearing test, blood tests, including single nucleotide polymorphism array (SNP array), along with other assessments according to the pediatrician's judgment; (2) parental interview regarding the child's developmental and medical history, current clinical symptoms and social situation, including trauma; (3) administration of the ESSENCE-Q-REV (Gillberg 2010); (4) testing using the Wechsler Preschool and Primary Scale of Intelligence, Fourth Edition (WPPSI-IV) (Wechsler 2012) for children over 2:6 years, and for younger children

Merrill-Palmer-Revised Scales of Development (MP-R) (Rod and Sampers 2005); (5) the Autism Diagnostic Observation Schedule Second Edition (ADOS-2) (Lord et al. 2012); (6) the Vineland Adaptive Behavior Scales Second Edition completed by the psychologist (VABS-II) (Sparrow et al. 2005); and (7) preschool observation, including JA-OBS Preschool. To determine the autism diagnosis, the criteria outlined in the DSM-5 (299.00, Autism Spectrum Disorder) were used (American Psychiatric Association 2013).

3.7.2 THE INTERVENTION PROGRAM BASED ON THE ESDM

In the intervention program, ESDM strategies were used by the parents and preschool staff in the child’s natural settings for 24 months. A certified ESDM therapist⁷ coached the parents and the preschool staff, assisting them in the program’s objectives and ESDM strategies into the everyday caregiving, play activities, and routines at home and in preschool (Rogers and Dawson 2010; Rogers et al. 2021). To enhance effectiveness, some adjustments were implemented, including simplification of the objectives, while ensuring that all fundamental aspects of the ESDM methodology were maintained.

The intervention program includes three steps (Figure 1).

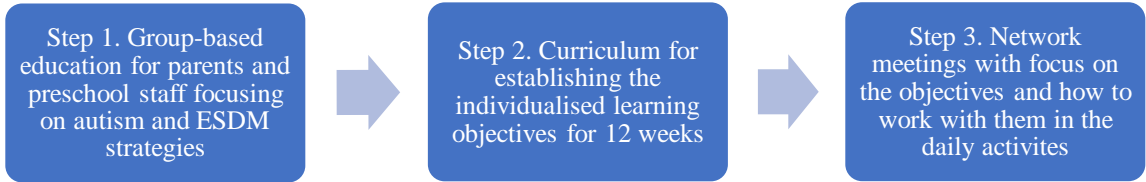


Figure 1. The intervention program based on the ESDM and the different steps (step 1-3)

Step 1. Group-based education for parents and preschool teachers

The parents and preschool staff were engaged in an education program centered on autism and ESDM strategies. The education comprised information of autism indicators, underlying factors contributing to autism, and co-existing conditions. Additionally, it provided a theoretical background on ESDM and strategies for

⁷ In the intervention program, there were three therapists, two of whom were certified ESDM therapists. The third therapist has worked with interventions for young children with autism for 26 years and has experience with both the ESDM and methods, according to the EIBI. However, in the intervention program, she worked with interventions according to the ESDM. She has several courses in the ESDM. Furthermore, she also received supervision from the certified ESDM therapists.

fostering avenues of communication and interaction within the daily routines. For the parents, the education spanned 3 hours over two different occasions. The preschool education was a digital interactive presentation and included a single session of 3.5 hours.

Step 2. The ESDM Curriculum Checklist for Young Children with Autism for establishing the individualized objectives

The ESDM curriculum was used to widely assess the child's skills across various developmental domains (receptive communication, expressive communication, imitation, play, joint attention, social skills, cognition, fine motor, gross motor, behavior, and personal independence) and to establish individualized teaching objectives. The ESDM therapist utilized the curriculum to formulate specific objectives for the child. These objectives were also based on the parents' learning profile and identified priorities, i.e. areas deemed particularly important to work on within the home environment (Vivanti et al. 2014b). Moreover, the preferences and prerequisites of the preschool, including available resources, were considered.

Step 3. Network meeting

Every second week, a network of individuals, including the child, the parents, the preschool staff, and the ESDM therapist, convened. While most meetings took place at the clinic, occasionally they occurred at home or preschool. The sessions followed a recurring structure, including a greeting ritual, playtime, song and rhymes, a break for snacks, book reading, and a goodbye ritual. The therapist guided both the parent and preschool staff on implementing the ESDM strategies and achieving the objectives in the child's day-to-day life. The child's daily activities involved tasks such as bathing, reading books, dressing/nappy changing, household tasks, meals, outdoor activities sensory, social routines, and playing with toys. Additionally, the preschool activities included playing with toys, group activities, song and rhymes, book reading, outdoor activities, meals, care activities, and everyday activities.

3.7.3 PROCEDURES IN RECRUITMENT

In studies I-III, the study was presented to the parent/parents during the assessment visits. They were asked permission for their child to participate and received oral and written information about the study. In most cases, both the parents have signed the informed consent. Sometimes, only one guardian was able

to sign, as the other guardian resided abroad and had no/sporadic contact with the child.

In study IV, a purposive sample strategy was employed, specifically targeting participants aligned with the study's aim. Knowledge and experience of the intervention program based on the ESDM were required. Their consent was duly sought, accompanied by a thorough review of the study through both oral communication and written documentation. All participants, but one, accepted involvement in the study.

3.7.4 PROCEDURES IN DATA ACQUISITION

In studies I-III, data were collected from an ongoing longitudinal study. Two researchers independently reviewed medical records from CHC and the comprehensive neuropsychiatric assessment. The data were recorded in a study protocol and registered in an Excel spreadsheet.

In study IV, focus group interviews were conducted with the preschool staff. The preschool staff were divided into three groups; one group consisted of a special education teacher and principals, and two groups with preschool teachers and preschool care workers. Semi-structured interview guides with open-ended questions were used to capture the preschool staff's experiences of the intervention program based on the ESDM. The interview guide has been developed by abstracting the aim of the study, reviewing the literature, and using clinical experience, to form questions such as, *'Tell me about the work with the intervention program.'*, *'How have you worked with the strategies in everyday life?'* and *'What opportunities and obstacles have you experienced in working with the intervention program?'*. The interviewer was unknown to the participants, allowing them to talk more openly about their experiences. Each focus group met on one occasion and the interviews lasted 60-70 minutes. The interviews were held in Swedish. The interviews were recorded and transcribed verbatim.

3.8 DATA ANALYSIS

3.8.1 STUDY I

Descriptive statistics were used to describe the prevalence of autism. The prevalence was estimated on December 31, 2018. The calculations were presented as means, SD, and proportions.

3.8.2 STUDY II

Descriptive statistics were used to report data on feeding problems. To test associations between two binary variables, Fisher's exact tests and risk ratios (RRs) were calculated. To test associations between ordered categorical and binary variables, Kruskal-Wallis tests were computed. Welch's t-test was used to test group differences for continuous variables. Statistical significance was considered at a p-value of ≤ 0.05 . The calculations were completed in Stata 16.1 (StataCorp. 2019).

3.8.3 STUDY III

Descriptive statistics were used to report the psychometric properties of JA-OBS Preschool in children with suspected autism. Internal consistency reliability was calculated using Cronbach's alpha. Inter-rater consistency was calculated as percent agreement. The calculations were completed in SPSS version 27 (IBM Corp 2020).

3.8.4 STUDY IV

In study IV, the data were organized and structured with the software program NVivo 12 (Lumivero 2017). The interview texts were analyzed and interpreted following qualitative content analysis (Graneheim and Lundman 2004; Lindgren et al. 2020). During the structural analysis, the data was ordered into meaning units, which were subsequently condensed, i.e. effectively shortened while retaining their core content. When all material was analyzed and all meaning units detected, the units were labelled with a code. Following this, similarities, and differences between codes and across interviews were discussed, subsequently categorizing them into themes and subthemes. The data analysis entailed ongoing dialogues among the authors.

3.9 ETHICAL CONSIDERATIONS

All studies in this thesis comply with the principles in the Helsinki declaration from 1995, as revised in 2008. All studies were approved either by ethical review board in Gothenburg or by the Swedish Ethical Review Authority:

Study I-III: The Regional Ethics Committee in Gothenburg, Sweden (reference nr: 653-14, 549-17, 554-18).

Written informed consent to participate in this study was provided by the participants' legal guardian or next of kin.

Study IV: Swedish Ethical Review Authority (reference nr: 2022-03517-01).

Written informed consent to participate in this study was provided by the participants.

4 RESULTS

4.1 STUDY I

Study I set out to examine the prevalence of autism in preschool-aged children within a multiethnic immigrant population. Additionally, it aimed to describe the prevalence of potential risk factors associated with autism.

4.1.1 CHILDREN DIAGNOSED WITH AUTISM

On the census day, a total of 33 children (24 males, 9 females), born between 2013 and 2016, were identified at the CHC as having an autism diagnosis in accordance with the criteria outlined in the DSM-5. The male-to-female ratio was 2.6:1. Thirty-one children received their autism diagnosis subsequent to assessment conducted by the local team (23 males and 8 females), while two received their diagnosis at a different clinic.

All 31 children with autism exhibited co-existing symptoms, including other NDDs, and/or other medical conditions, including sleep and feeding difficulties, early signs of ADHD symptoms, and/or epilepsy. Two children had AIF, 9 BIF, and 20 children had ID.

4.1.2 PREVALENCE ESTIMATES

The estimated prevalence of autism among the 902 children, 2-5 years of age, within the multiethnic immigrant population was 3.7% (males 5.3%, females 2.0%). Detailed information regarding prevalence and the corresponding number of children diagnosed with autism across various age groups can be found in Table 5.

Table 5. Autism prevalence rates in different age groups in the study population (n=902)

Birth year	Number of children registered at CHC	Number of children diagnosed with autism (male-to-female ratio)	Autism prevalence (male-to-female ratio) (%)
2013	227	12 (8:4)	5.3 (7.0:3.5)
2014	229	13 (11:2)	5.7 (9.8:1.7)
2015	234	4 (2:2)	1.7 (1.7:1.7)
2016	212	4 (3:1)	1.9 (2.7:1.0)

Following the census day, six children were identified with autism. Taking these cases into account, the projected prevalence of autism among children aged 2 to 5 within the immigrant population stands at 4.3%.

4.1.3 PRE-/PERINATAL RISK FACTORS FOR AUTISM

The utilized risk factor classification system revealed potential risk factors in at least two of the five domains for all children. Risk factors were discerned in three areas in 15 children and in four areas for seven children. Maternal migration status (28 children) and other prenatal risk factors (24 children) emerged as the most common risk factors.

Regarding maternal origins, 12 hailed from East Africa, seven from South/East Asia, seven from West Asia, three from North Europe, and two from North Africa. Twenty-five mothers had migrated more than a year prior to the child's birth, and four children had been born abroad. Fourteen mothers originated from regions with low HDI.

In addition to maternal migration, 24 children exhibited at least one other prenatal risk factor. The most common was parity first, fourth, or more (19 children). Three children had a father older than 40 years. A clustering of pregnancy complications was identified in seven mothers, including preeclampsia and mental health problems. All pregnancies involved singletons.

Sixteen children exhibited at least one perinatal factor, the most common was clustering of birth complications (10 children), including caesarean section and vacuum extraction. The majority (27 children) were born after full-term pregnancy. Four children were born prior to the 37th week of gestation. Three children had birth weight <2500 g, and as many had a birth weight >4000 g. Four of the children were considered small for gestational age. Five children needed neonatal care, due to prematurity, feeding difficulties, hyperbilirubinemia, and/or neonatal sepsis.

Among 31 children, 18 children had a first and/or second degree relative with autism and/or other NDDs. Within the study group, 9 children had a first/second degree relative with autism or strong suspicion of autism. Fifteen children had a relative affected by other NDDs. Genetic analyses disclosed an elevated degree of homozygosity, consistent with consanguinity, in three children, while one child exhibited a deletion on chromosome 10 (the clinical significance of which remains uncertain). Minor physical anomalies (MPA) raised suspicion of a medical syndrome in three children.

4.1.4 SUMMARY STUDY I

The autism prevalence was estimated at 3.7%, which is probably an underestimate given the higher rates in slightly older children. Multiple risk factors for autism were observed, including genetic and non-genetic factors.

4.2 STUDY II

Study II was designed to examine feeding problems in preschool-aged children with autism. The overarching objectives encompassed a comprehensive exploration of (a) the prevalence of feeding problems, (b) the prevalence and characteristics of ARFID within this group, and (c) an in-depth analysis of the age of onset and potential early indicators signaling the development of feeding disorders in individuals with autism.

4.2.1 DISTRIBUTION OF FEEDING PROBLEMS AND DISORDERS

Thirty-five (76.1%) of 46 children with autism had feeding problems (Figure 2). Feeding difficulties were found in 10 children (21.7%) and feeding disorders in another 25 (54.3%) (19 males, 6 females), 13 (28.2%) of whom had ARFID (9 males, 4 females).

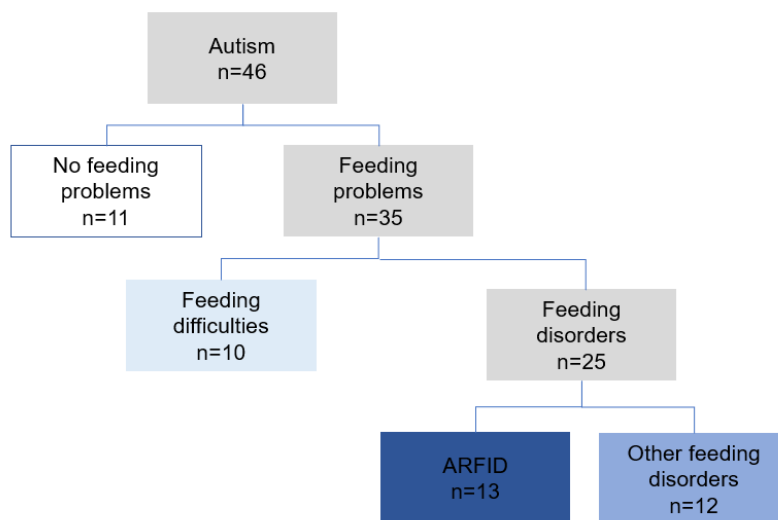


Figure 2. Feeding problems in children with autism (n=46)

4.2.2 CLINICAL CHARACTERISTICS OF CHILDREN WITH AND WITHOUT FEEDING PROBLEMS

There were some significant differences between the children with and without feeding problems. Children with feeding problems had lower mean birth weights ($M = 3\,142$ g, range 1 690–4 280 g, SD 604 g), compared to those without feeding problems ($M = 3\,835$ g, range 3 150–4 790 g, SD 427 g) ($t = 4.22$ (23.8), $p <$

0.01). Children with feeding problems had a greater degree of autism severity ($p < 0.01$). On the ESSENCE-Q, children with feeding problems had a higher average total score ($t = 2.3$, $p = 0.024$, Cohen's $d = 0.81$, 95% CI 0.1–1.5), and more often experienced difficulties with sensory reactions ($p = 0.03$).

4.2.3 CLINICAL CHARACTERISTICS OF CHILDREN WITH AND WITHOUT ARFID

All 13 children with *ARFID* exhibited an apparent lack of interest in eating or in food and avoidance based on the food sensory characteristics. Among the children diagnosed with ARFID, 12 met the diagnostic criterion A1, viz a significant weight loss (or failure to achieve expected weight gain or faltering growth in children). Ten of the 13 children had registered a BMI ≤ -2 SD. Criterion A2, a significant nutritional deficiency and/or insufficient nutritional intake according to diarized daily logs, was met in ten of the 13. Three children presented with an iron deficiency necessitating treatment, 9 required oral dietary supplements (criterion A3), and 11 had feeding behaviour that markedly interfered with their psychosocial functioning (criterion A4). Five children concurrently experienced one or more documented coexisting medical conditions associated with feeding (food allergy, adenoid hypertrophy, oral motor difficulties, and/or operated cleft palate).

In children with ARFID, the feeding problems occurred very early, and in 9 children during the first year. At follow-up two years after autism diagnosis, four out of the 13 no longer met the criteria for ARFID.

Twelve children exhibited *other feeding disorders* other than ARFID. Also, within this group, some children displayed a lack of interest in eating or food and/or had selectivity in food choice (eight children), but not to the degree that the criteria for ARFID were fulfilled. One child had a BMI of ≤ -2 SD, and one received treatment for iron deficiency. One or more known medical conditions, including multiple food allergies, tonsil- and/or adenoid hypertrophy related to feeding, were found in seven of these 12 children. In four of these children, the feeding problems had manifested during the child's first year. At follow-up, 9 out of the 12 no longer met the criteria for a feeding disorder.

4.2.4 EARLY SYMPTOMS AND PRODROMAL SIGNS IN FEEDING DISORDERS

Twenty-two of the 46 children with autism had persisting RPs beyond three months of age. The presence of RPs significantly increased the likelihood of subsequent feeding disorders (RR = 2.32; 95% CI 1.26–4.26). RPs concerning eating were found to significantly increase the risk of later feeding disorders. (RR = 2.11; 95% CI 1.32–3.38).

4.2.5 SUMMARY STUDY II

Feeding problems, including ARFID, were prevalent in these children with autism. Persisting RPs, particularly eating-related RPs, along with unusual sensory reactions were more frequently observed in these children who also had comorbid feeding problems.

4.3 STUDY III

Study III aimed to explore the psychometric properties of the JA-OBS Preschool in children with suspected autism.

4.3.1 RESULTS OF THE JA-OBS PRESCHOOL

Of the 46 children with autism, 41 had been observed with the JA-OBS preschool, and all of them had screened positive, i.e. “failed” on two or more of the seven items. Of the 41 children, 31 failed on six or more of the items. The failure rate on individual items ranged from 29/41 through 40/41.

Internal reliability was analyzed for all items and estimated at 0.80 (Cronbach’s alpha).

In 13 children, percent agreement was computed by comparing the independent assessments of two different raters. All children screened positive for autism when the raters completed JA-OBS Preschool. Percent agreement for respective items ranged from 76.9% to 100% (Table 6).

Table 6. Number of failures on individual item for each rater and percent agreement between two raters in JA-OBS Preschool (n=13)

JA-OBS Preschool	Number of failures on individual item for each rater, n (%)		Inter-rater consistency
	Rater 1 ¹	Rater 2 ²	Percent agreement
Item 1	10 (76.9)	11 (84.6)	76.9
Item 2	12 (92.3)	13 (100)	92.3
Item 3	12 (92.3)	12 (92.3)	84.6
Item 4	11 (84.6)	10 (76.9)	76.9
Item 5	12 (92.3)	11 (84.6)	76.9
Item 6	13 (100)	12 (92.3)	92.3
Item 7	13 (100)	13 (100)	100

¹The psychologist from the multidisciplinary assessment team

² Special education teachers from preschool

Item 1 Does the child react to their own name (turns to person addressing the child)?

Item 2 Does the child try to establish eye contact with you?

Item 3 Does the child gaze at something that you point to further away in the room?

Item 4 Does the child use his/her index-finger to point at something (e.g. in a book)?

Item 5 Does the child interact with you or parent in pretend play (e.g. during feeding a doll, or putting the doll to bed; does the child use eye contact to monitor that you are watching)?

Item 6 Does the child show interest in other children?

Item 7 Does the child take some initiative to contact other for play, to show something, to tell something, not just because other are looking for contact?

4.3.2 SUMMARY STUDY III

All children with suspected autism screened positive on the JA-OBS preschool. The internal consistency reliability was calculated at 0.8 (Cronbach's alpha). Percent agreement for individual items ranged from 76.9% to 100% when two independent raters conducted the observations of one and the same child.

4.4 STUDY IV

Study IV aimed to describe an intervention program based on the ESDM within a multiethnic immigrant context, while also seeking to encapsulate the insights and perspectives of the preschool staff engaged in implementing the program.

4.4.1 A PRESCHOOL FOR ALL CHILDREN

According to the preschool staff' narratives, the analysis revealed four main themes and 10 corresponding subthemes pertinent to the objectives. The overarching theme was "*A preschool for all children – the ESDM as a tool*". The initial facet of this theme encapsulated the participants' experiences that the intervention program significantly enhanced the educational milieu for children with autism. The participants articulated that the ESDM proved tools in establishing a preschool environment where children, including those with autism, obtained stimulating and challenging learning experiences.

The four main themes that emerged were: (1) "*The ESDM – everyday network around the child*", (2) "*General key element*", (3) "*Challenges for preschool staff*", and (4) "*The sum is more than the parts – 1+1=3*". Table 7 lists the main themes and subthemes.

Table 7. Overview of the overarching theme, main themes, and subthemes (n=15)

<i>A preschool for all children – the ESDM as a tool</i>			
The ESDM – everyday network around the child	General key elements	Challenges for preschool staff	The sum is more than the parts – 1+1=3
Shared objectives and collaboration	Principal’s role – to create prerequisites for the collaboration	Communication with parents about the child’s development - the role of knowledge mediator	Valuable for several – for the child with autism, the other preschool children, and the parents
Easy to adapt to the preschool curriculum and in daily activities	Local team as a resource - only a phone call away	Not just one child with autism – to provide education for all the children	Improved collaboration - increased communication and consensus around the child’s needs
	Knowledge of each other’s missions and responsibility		New knowledge creates security

4.4.2 THE ESDM – EVERYDAY NETWORK IN DAILY ACTIVITIES

The first main theme centered on the ESDM as the intervention model and comprised two subthemes. These subthemes delved into crucial facets of the ESDM. The participants empathize the significance of shared objectives and regular network meetings as integral components. For example, the network played a pivotal role in fostering enhanced collaboration and communication with the parents. Also, the preschool staff felt that they gained heightened competence, which benefited all children in the preschool.

Furthermore, the main theme also revealed an alignment between the ESDM and the preschool curriculum. *“If you had to find objectives for the curriculum /.../ this would not be a problem for all exercises.”*. Additionally, participants attested to the ease with which ESDM strategies seamlessly integrated into the day-to-day routines of the preschool.

4.4.3 GENERAL KEY ELEMENTS

The second main theme, *General key elements*, comprised three subthemes. The subthemes focused on fundamental prerequisites essential to the intervention program, including the principal's role and the locally located team, i.e. the multidisciplinary team.

The participants underscored the pivotal role of the principal's attitude and active involvement in the program. It was deemed crucial that the principal take concrete steps to facilitate the participants' involvement, for instance, the network meetings. *"It is up to the principals to give us those conditions. /.../ That you can bring in someone to cover."*

Another part of this main theme was the therapists' availability for both support and supervision. Additionally, the participants highlighted the team's local location as prerequisite for effective collaboration.

4.4.4 CHALLENGES FOR PRESCHOOL STAFF

The third main theme encapsulated two facets of challenges inherent to the pedagogical role. The first aspect revolved around communication with the parents, while the subsequent aspect focused on the high prevalence of children with autism in the area. *"You don't always know how to express yourself either /.../ Can I talk about the word difficulty with this parent or can I not."*

The participants had noticed that a considerable number of children had autism or other NDDs. They grappled with the complexity of providing education that catered to the diverse needs of both children with and those without disabilities.

4.4.5 THE SUM IS MORE THAN THE PARTS – $1+1=3$

The fourth main theme, *"The sum is more than the parts – $1+1=3$ "*, was related to the effect of the intervention program and comprised three subthemes. The title highlights that the intervention program yielded benefits not only for the children with autism but also extended its positive effects to their peers in the preschool, their parents, and the preschool staff. For example, the network contributed to heightened collaboration and improved communication with parents. *"Then we end up in those dialogues, where we don't understand each other. It's not just us and when you come here and can talk and open up everything."*

The participants noted that the ESDM had a positive impact on the children with autism, such as increased communication. Additionally, the ESDM proved

advantageous for other children in the preschool. Given that most of the children spoke a home language other than Swedish, the ESDM offered them valuable chances to develop their vocabulary and communication abilities. Furthermore, the participants themselves gained increased competence, which not only benefited other children but also facilitated the early recognition of signs indicative of autism in children. *“Working with new children is not so difficult. You know what to do.”*

4.4.6 SUMMARY STUDY IV

The preschool staff experienced that the intervention program based on the ESDM had yielded substantial benefits for children with autism, their parents, their peers in the preschool, and for themselves. They found the ESDM easy to adapt to the preschool curriculum and everyday life. Moreover, their participation increased the child’s intervention time and enriched learning opportunities, fostering skill generalization across diverse settings and with other adults. The participants underscored some key factors that influenced their efforts in the implementation of the ESDM, including the principal’s role in creating organizational prerequisites, and the ESDM therapist’s availability for supervision and support.

5 DISCUSSION

The research presented here was conducted in a multiethnic and socioeconomically deprived area in Gothenburg, Sweden. Research on children with autism within immigrant communities has been limited, making it imperative to address various pressing issues. These include identifying factors associated with the increased risk of autism in immigrant populations as well as devising strategies for delivering equitable care to these groups.

In study I, the research revealed an estimated prevalence of autism among children aged 2-5 years to be almost 3.7%. Multiple risk factors for autism were identified, including genetic and non-genetic factors. Study II found that feeding problems, including ARFID, were prevalent in children with autism. Furthermore, persistent RPs, specifically eating-related RPs, and atypical sensory reactions were found to be more common in children with the combination of autism and comorbid feeding problems. In study III, the JA-OBS Preschool emerged as a promising instrument for detecting indications of autism within a preschool setting. Study IV focused on prerequisites for implementing an ESDM intervention program in a preschool setting, including the preschool staff's participation fostered by the local environment and features linked to the ESDM methodology. The discussion will delve into various facets of these findings and their potential clinical implications.

5.1 STUDY I

In the 1970s and 1980s, a raised risk of autism in children of immigrants was first described in Sweden, the United Kingdom, and Australia (Dealberto 2011; Gillberg et al. 1987). Study I found a high autism prevalence in the studied multiethnic immigrant area, and this agrees with results from other studies in recent years (Crafa and Warfa 2015; Kawa et al. 2017; Schmengler et al. 2021). Nevertheless, the specific risk factors contributing to the link between parental immigrant status and the development of autism in offspring remain unclear.

The genetic heritability of autism is suggested to play a fundamental role in its onset, together with environmental and epigenetic factors (Masini et al. 2020). Twin and family studies further indicate the high heritability of autism (Masini et al. 2020; Sandin et al. 2017; Taylor et al. 2020). Bolton et al. (2014) have demonstrated a high rate of family history of autism (36.9%) in an African cohort. In our study, multiple risk factors were observed, including maternal immigrant status, clustering of pregnancy and birth complications, family history risk, and genetic risk factors for autism. Of the children, 29% had a first/second degree relative affected by autism or with a strong suspicion of autism. Additionally, various prenatal and perinatal risk factors were identified in the study group. Previous research has shown that suboptimal pregnancy and birth conditions can contribute to the development of autism and other neurodevelopmental conditions (Bolte et al. 2018; Carlsson et al. 2021; Coleman and Gillberg 1985).

It has been posited that the timing and circumstances of migration may play a role in autism disparities within immigrant populations, along with the parental region of origin (Magnusson et al. 2012; Schmengler et al. 2019). Furthermore, other factors, including well known pre-, peri-, and postnatal risk factors for autism, have been discussed (Gillberg et al. 1995; Masini et al. 2020; Modabbernia et al. 2017). For instance, immigrants may differ from the indigenous population in risk factors, including maternal obesity, socioeconomic status associated with inadequate housing and poor nutrition, and exposure to environmental pollutants (Delobel-Ayoub et al. 2015; Murphy et al. 2017; Rauh and Margolis 2016; Sanchez et al. 2018). In addition, immigrants may face language and cultural barriers, potentially contributing to delayed treatment of pregnancy complications (Heaman et al. 2013; Modabbernia et al. 2017).

A growing body of evidence has proposed that maternal and neonatal vitamin D deficiency may be associated with an elevated risk of autism (Kočovská et al. 2012; Lee et al. 2021; Upadhyaya et al. 2022; Wang et al. 2020). Unfortunately, data on maternal and neonatal Vitamin D status were not available in this study. Nevertheless, Vitamin D deficiency is prevalent worldwide, particularly in pregnant women, and is more common in regions with higher latitudes,

immigration to such areas, urban residence, and regions with greater precipitation (Mansur et al. 2022). Vitamin D is a neuroactive hormone essential for normal brain homeostasis and neurodevelopment (Eyles et al. 2011). There is a mutuality between the Vitamin D system and epigenetic mechanisms. The vitamin D system is both regulated by epigenetic mechanisms and involved in regulating epigenetic events (Forouhari et al. 2023). Epigenetic mechanisms may activate the interaction between Vitamin D and other non-genetic factors, including advanced paternal age, maternal stress during pregnancy, and genetic factors. Vitamin D supplementation has also been suggested to be associated with reducing adverse pregnancy outcomes, including autism (Cheng et al. 2019). However, further research is needed to understand the role of vitamin D in the risk of autism in offspring.

A timely diagnosis of autism and early interventions may lead to improved long-term outcomes by leveraging the brain's neuroplasticity at a younger age (Ismail et al. 2017; Zwaigenbaum et al. 2019). However, there are barriers to accessing equal healthcare and support in immigrant populations, resulting in delayed or missed autism detection, diagnosis, and interventions (Schmengler et al. 2021; Sritharan and Koola 2019). Thus, there is an urgent need to develop new care models for children with autism and their families. Earlier studies have indicated that both social and cultural factors (e.g. stigma, discrimination, limited understanding of the healthcare system, and lack of social support) and structural and socioeconomic factors (e.g. transportation limitations, financial constraints, and language barriers) constitute potential obstacles to the early detection of autism signs, access to assessment and interventions (Nilses et al. 2019; Schmengler et al. 2021; Sritharan and Koola 2019). The studies presented in this thesis emphasizes the importance of developing innovative models to enhance care accessibility to care for children with autism in immigrant communities.

Providing free and universal healthcare and social support alone may not be sufficient to reach all immigrant families. For instance, Fox et al. (2017) discovered that unfamiliarity, a fragmented system within health, education, and social care services, as well as language barriers, contributed to delays for Somali families in accessing support for their children with autism. In this thesis, a local collaborative assessment and intervention program is presented. An essential part of this program is preventing fragmented and dispersed care and increasing continuity in health care, specifically by enabling assessment and interventions close to the family, in collaboration with CHC and the preschool.

Cultural values and beliefs influence perceptions of autism and children's development in general. Parents of children with autism from different ethnic backgrounds may express varying concern when their child exhibits potential autism symptoms (Golson et al. 2022). In addition to integrated care, this study

underscores the importance of equipping healthcare professionals with both knowledge of NDDs and awareness of how cultural beliefs may influence views on the child's development. A culturally sensitive approach may facilitate the early detection of autism signs, leading to a more personalized and family-centered program that can accommodate the unique needs of immigrant families, ultimately enhancing accessibility to autism care. In the subsequent sections of this thesis (5.3 and 5.4), the pivotal role of preschools will be delved.

5.2 STUDY II

Eating and feeding problems, including picky eating, food avoidance, fear of trying new foods and insistence on specific food, are common in children with autism (Baraskewich et al. 2021). Bourne et al. (2022) found that ARFID is a significant problem among children with autism. Study II found that 76.1% of the children with autism faced feeding problems, with 28.2% meeting criteria for ARFID. Among those with ARFID, the onset of feeding problems occurred at a very early age and in nearly 70% of these children the criteria for ARFID were still fulfilled at follow-up. Additionally, these feeding problems were notably severe, necessitating extensive healthcare involvement, including prolonged use of nutritional supplements. Still, the research is limited, particularly in understanding the prevalence and underlying causes of ARFID in general and particularly in children with autism. Nevertheless, the existing knowledge can be applied in clinical settings to facilitate early detection, assessment, and intervention efforts.

Persistent RPs have been recognized as potential indicators of later NDDs (Hemmi et al. 2011; Schmid et al. 2010). Study II's results also demonstrated that nearly 50% of the children had persisting RPs before receiving an autism diagnosis. Furthermore, eating related RPs and early atypical sensory reactions were identified as factors increasing the risk of subsequent feeding disorders. Together with earlier research, these findings hold practical implications for clinical practice. For instance, when the clinician meets a child with persistent RPs, it may prompt consideration of autism and/or other NDDs (Schmid et al. 2010). Similarly, in cases of severe feeding problems in general, especially in children with ARFID presentations and sensory sensitivities, it is crucial to explore the possibility of co-occurring autism and/or other NDDs (Bourne et al. 2022; Johansson et al. 2023). Furthermore, when assessing children with autism in healthcare settings, the clinician must be vigilant about the high rates of coexisting medical conditions and feeding problems (Baraskewich et al. 2021; Muskens et al. 2017; Pan et al. 2021). Consequently, children exhibiting persisting RPs, unusual sensory reactions, early feeding problems, early social communications deficits, and/or any other ESSENCE symptoms must be closely followed and broadly assessed. A collaborating effort across various professionals is essential to ensure thorough evaluations. Chao (2022) has proposed that a multidisciplinary framework combining medical, oral motor, behavior, sensory, and environmental consideration to aid in assessing feeding problems in children with autism.

Additionally, interventions must encompass a holistic approach, addressing both autism core symptoms and co-occurring conditions, as well as external factors impacting the child, including parental health, economic constraints, and

overcrowding. Understanding and identifying factors contributing to feeding problems empowers healthcare professionals to determine the most appropriate treatment. In this context, a multidisciplinary approach has been recommended as an effective strategy in supporting children with autism and feeding problems (Bourne et al. 2022; Esposito et al. 2023).

In addressing feeding or eating problems, it is imperative to acknowledge the role of caregivers, including parents and preschool staff. Feeding problems evoke significant concern for parents and can affect both the child's development and functioning and daily life of parents potentially leading to increased stress levels (Baraskewich et al. 2021; Esposito et al. 2023). It is important to understand the context in which the feeding problems occur and how they affect the child's daily functioning. Feeding problems may likely be included in the targeted interventions for children with autism, and sometimes it is necessary to involve specialized expertise, including pediatricians and/or dieticians, working alongside the caregivers.

5.3 STUDY III

The early detection of autism is crucial for enabling timely diagnosis and interventions (Zwaigenbaum et al. 2019). Research has suggested that children from immigrant backgrounds may face delays in receiving diagnoses, potentially causing them miss out on beneficial early interventions (Schmengler et al. 2021). Several studies have posited that autism signs can be discerned in preschool settings, even in socioeconomically disadvantaged and culturally diverse environments (Gulsrud et al. 2019; Janvier et al. 2016; Zhang et al. 2019).

Screening tools play a crucial role in identifying children who may need a more comprehensive diagnostic evaluation. The American Academy of Pediatrics advocates for the use of standardized screening tools for autism at the 18- and 24-month pediatric well visits (Siu et al. 2016). In Gothenburg, all 30-month-old children are invited for autism screening at the CHC (Central Barnhälsovård Västra Götalandsregionen 2018). This screening encompasses the parental questionnaire M-CHAT-R/F alongside clinical observations using JA-OBS (Nygren et al. 2012). Additionally, alternative settings like preschools, might serve as valuable supplements to the CHC-based screenings, especially within immigrant populations. Firstly, most children in Sweden attend preschool from an early age (Skolverket 2022). Secondly, the preschool staff are well-positioned to interact and observe the child when playing with peers in structured playing environments. Thirdly, they possess extensive knowledge and training in child development, enabling them to identify deviations from typical development. In Swedish preschools, the preschool staff ensure that each child's development and learning is systematically and continuously documented (Skolverket 2018). Furthermore, regular parent-preschool staff meetings prioritize discussions about the child's development and learning, including any development concerns.

Nevertheless, implementing early detection methods in preschool settings necessitates certain prerequisites, including valid instruments, established protocol for their use, and access to healthcare services assessment and interventions. In the current study, the JA-OBS Preschool demonstrated promise as an instrument for identifying autism within the preschool settings. The internal consistency reliability of the JA-OBS Preschool was estimated at 0.8 (Cronbach's alpha) with percent agreement across raters ranging from 76.9% to 100%. However, future research is required to ascertain the psychometric properties of the JA-OBS Preschool in a general child population and in younger children.

In addition to valid instruments, ongoing education and supervision are imperative for preschool staff. This education should focus on the child's communication and interaction development, early autism signs, and the proper

utilization of the instrument in preschool settings. Screening instruments may help preschool staff make well-informed and more confident decisions. In my clinical experience, preschool staff often encounter difficulties in discussing a child's atypical development with the parents. Hence, it is essential to equip them with the support and knowledge necessary to broach their concerns tactfully. While some parents may share the staff's concerns, others may not be ready to hear that their child has a deviant development. In this endeavor, it is important to consider how sociocultural expectations and family experiences shape perceptions of a child's development and autism (Kärtner et al. 2020; Schmengler et al. 2021; Selman et al. 2018).

Moreover, the JA-OBS Preschool should be employed in a context where avenues for intervention and assessment are available. Study I highlighted a model aimed at increasing accessibility to healthcare services for children with autism in immigrant communities. Routines for early detection in preschools could be an integral component of this model. Earlier research has proposed that implementing routines for early detection of autism in preschool settings may alleviate linguistic, cultural, socioeconomic, health literacy barriers, particularly within vulnerable populations, including immigrant settings (Gulsrud et al. 2019; Janvier et al. 2016).

Furthermore, the active involvement of preschool staff in early detection leads to heightened knowledge and awareness regarding young children with autism. Identifying children with autism at an earlier stage ensures they become more visible into the everyday life of the preschool. Additionally, the enhanced knowledge and awareness prove invaluable in the implementation of early interventions, making preschool staff an indispensable part of the intervention process. Study IV explored the experiences of preschool staff when collaborating with parents and healthcare professionals in intervention efforts.

5.4 STUDY IV

Early interventions for young children with autism have been shown to enhance developmental outcomes (Schreibman et al. 2015; Zwaigenbaum et al. 2015a). The ESDM stands as one of the most well-established intervention models for young children, demonstrating promising results, including improvement in core developmental domains and reduction of maladaptive behaviors (Dawson et al. 2010; Fuller et al. 2020). Moreover, the ESDM has shown positive outcomes in various domains when implemented in preschools, including social interaction, language skills, overall cognitive development, and adaptive functioning (Sinai-Gavrilov et al. 2020; Vivanti et al. 2019).

Despite the potential benefits, opportunities for interventions for children with autism are often lacking, particularly in immigrant communities (Amant et al. 2018; Schmengler et al. 2021). In the study area, children with autism and their parents, in collaboration with preschool staff, were provided an intervention program based on the ESDM. The present study aimed to capture the preschool staff's experiences regarding the intervention program.

The analysis underscored the pivotal role of ESDM itself as a key factor in the intervention program's implementation within the preschool setting. The participants emphasized the seamless alignment between the ESDM and the preschool curriculum emphasizing how ESDM strategies could be easily integrated into the preschool's daily routines. Play-based learning and the cultivation of relationships with an emphasis on language and communication were central tenets within both the preschool curriculum as well as in the ESDM (Rogers and Dawson 2010; Skolverket 2018). Previous studies have reported challenges in implementing other interventions model in regular preschools such as the EIBI (Långh et al. 2017; Roll-Pettersson et al. 2016). In a study by Kvick (2020), the preschool staff described hindrances in collaboration with healthcare services, including differing perspectives on learning, challenges in aligning goals within the preschool activities, and the transfer of the child's skills from a training situation to daily activities. In addition to the ESDM, some other aspects that may have facilitated the intervention program's implementation in the preschool setting will be discussed.

Vivanti et al. (2018) have identified factors, including infrastructure and resources, staff motivation/commitment, and organizational leadership, as influencing intervention implementation in preschool. In this study, contextual factors were addressed, including the principal's role and the availability of healthcare team. The preschool staff underscored the importance of the multidisciplinary team's local attachment in participating in the interventions. In the intervention program based on the ESDM, the active involvement of parents

and preschool staff was fundamental, as they incorporate the objectives and ESDM strategies in the child's daily routines. Furthermore, Zwaigenbaum et al. (2015a) have emphasized the crucial role of active involvement from families and/or caregivers in interventions. This collaboration contributed to increased opportunities for the child with autism to generalize learned skills across different adults and settings, resulting in an increased amount of intervention time and learning opportunities. This is particularly significant, as many children spend substantial hours in preschool. Additionally, in immigrant communities, there are socioeconomic and cultural barriers that may affect parents' possibilities to maintain intensive treatment schedules (Pham and Charles 2023; Stahmer et al. 2019). Despite these challenges, implementing interventions in preschools may contribute to children with autism in immigrant communities receiving essential interventions.

The therapist's expertise and understanding of both the preschool curriculum and daily life were instrumental in fostering collaboration and implementing interventions in the preschool setting. This knowledge facilitated the development of relevant goals tailored to the preschool environment. Additionally, it played a crucial role in bridging the teaching approach and the medical perspective of healthcare. For instance, the medical terminology needed to be translated into the educational language of preschoolers, and tasks had to be adapted to group settings. In this endeavor, the presence of a certified ESDM therapist is essential to ensure method fidelity, thereby providing a high-quality intervention.

Equally essential was the preschool staff's knowledge of autism and the ESDM. In a review of caregiver-implemented interventions, Tomeny et al. (2020) have underscored "building on the caregiver's competence" and "collaborative planning" as essential coaching components (page 175). In the ESDM-based intervention program, parents, preschool staff, and the ESDM therapist jointly determine the focus of their sessions. The shared objective-setting was pivotal and contributed to the perception that the ESDM was easily applicable in the preschool setting. Moreover, the fact that the objectives were designed based on the priorities and characteristics of both parents and the preschool staff facilitated the implementation (Vivanti et al. 2014b). Another coaching component highlighted by Tomeny et al. (2020) was "guided practice" (page 175). In our study, the preschool staff emphasized the importance of network meetings. During the sessions, the ESDM therapist provided opportunities for both preschool staff and parents to employ strategies with the child, offering constructive feedback and support.

To summarize, several critical factors are essential for implementing interventions for children with autism in a preschool setting. Firstly, an evidence-based intervention method should be used, but it has to be adaptable to the preschool

context. The ESDM strategies seem feasible for integration into the preschool daily routines and aligned with its curriculum. Secondly, contextual prerequisites are required, for instance, organization support, close collaboration with healthcare, as well as competence of the preschool staff.

As previously mentioned, the collaboration between parents, preschool staff, and healthcare professionals was pivotal in the ESDM-based intervention program. The preschool staff reported that this network enhanced collaboration and communication with the parents. In a study by Khanlou et al. (2017), immigrant mothers with children with autism expressed displeasure with the discordance between healthcare services, social services, and the school system. Study IV aimed to encapsulate the perspectives of the preschool staff. In the subsequent study, we gathered the parents' experiences with the intervention program and their reflections on their collaboration with the preschool staff and healthcare professionals. We have conducted interviews in the hope that they shed light on this issue. This study is scheduled for publication in the near future.

5.5 STRENGTHS AND LIMITATIONS

The primary strength of these studies lies in their dedicated focus on an often neglected research population: young children with autism in an immigrant and low SES setting. All the involved children have been assessed by the same team, consisting of medical, psychological, educational and speech therapy professionals, each with considerable experience of young children with NDDs. Furthermore, a consistent set of diagnostic instruments and diagnostic criteria has been applied throughout the studies in this thesis.

Studies I-III relied on medical records, and the quality of these is of paramount importance. In the studies, two and the same experienced pediatricians had met all children. In the clinical assessment, a medical journal template had been used to ensure that different areas of development have been covered. These measures were used to enhance the reliability and accuracy of the data used in these studies. Unfortunately, specific data, such as maternal Vitamin D status, tobacco smoking, toxins, or illness during the pregnancy, were not available. For some children, certain data was missing, including JA-OBS Preschool results.

In study I, a small number of participants from a relatively small district of Gothenburg was included. Consequently, the findings may not be readily generalizable to the broader population of immigrant children. This also curtailed the ability to make statistical calculations. Therefore, future research endeavors with larger and more geographically diverse samples are warranted. In study III, one notable limitation is that the sample consisted of children who had undergone a screening, indicating a suspicion of autism. This factor likely influenced the high degree of agreement observed across the raters. Further studies are necessary to ascertain whether the observation process possesses a comparable capacity to confirm the absence of autism indicators, i.e. specificity.

Study IV used a qualitative methodology, and the findings reflected the participants' subjective, individual experiences. More research is necessary to evaluate the utility and efficacy of the intervention program in other settings.

5.6 ETHICAL CONSIDERATIONS

The immigrant group referred to in this thesis is heterogeneous, comprising individuals with varying origins, cultural beliefs and values and unique historical experiences. In research, immigrants are often described as one group, occasionally compared to non-immigrants as a uniform reference point. However, it is imperative to acknowledge and account for the substantial diversity that exists within this population. In the clinical settings, it is vital to approach each child and family based on their distinctive characteristics. Simultaneously, we must remain cognizant that their beliefs and values may differ from the assumptions that prevail in our culture.

I will now address some ethical considerations pertinent to the present studies. Firstly, the study population, young children with autism in a multiethnic immigrant population can be considered vulnerable. We have taken great care to make clear what participation in the study would mean. In cases, when necessary, we have used an interpreter to ensure that parents fully grasp the scope of their involvement. In research endeavors, it is imperative to include participants from diverse populations. Unfortunately, non-Swedish-speaking participants are often excluded from studies, potentially yielding findings that may be less representative. Moreover, the gathered data encompasses sensitive information, such as IQ scores, NDDs within the family, ethnicity, and genetic findings/syndromes. Nevertheless, the insights gained in this project are essential, contributing to a novel understanding of assessing and delineating models that enhance accessibility to care for this particular demography. Consequently, clinicians and researchers must exercise meticulous care when dealing with such sensitive research data.

Finally, there are instances where the data is presented at an individual level, potentially giving rise to ethical concerns. We have rigorously weighed the benefits against the risks of potential identifiability of individuals within the dataset. For instance, research pertaining to potential risk factors associated with autism in immigrant children is still in its nascent stages. If the risk factors are clustered early, there exists a risk of overlooking crucial due to limited knowledge. In research areas that are less developed, it is often imperative to provide more detailed reporting, elucidating the association between potential risk factors and autism in immigrant children. In cases where it has been deemed essential to report data at an individual level, we have taken measures to pseudonymize the data and employ overarching descriptors such as “East Africa” and “North Africa.”

6 FUTURE PERSPECTIVES

Diagnosing and treating autism in children of immigrants and those in non-Western countries presents significant challenges (Amant et al. 2018; Schmengler et al. 2021; Zeidan et al. 2022). In a review published in 2023 on autism in Africa, Aderinto et al. (2023) have outlined various obstacles to autism care in the continent, including limited awareness and education, lack of awareness and education, limited access to assessment and interventions services, stigma and social isolation. It is essential to develop culturally appropriate autism services, including screening, assessments, and interventions, to mitigate health disparities and surmount barriers to service accessibility. Within this endeavour, I will highlight two strategies aimed at alleviating obstacles and delivering services to this group of children and families.

Sritharan and Koola (2019) have described a culturally sensitive model for immigrant families with children affected by autism. This program identified barriers, including delayed diagnosis, limited access to services, and cultural beliefs regarding development and autism. Through culturally sensitive screening and assessment practices, conducted in collaboration with community pediatricians, immigrant families were able to access timely autism diagnostic and intervention services. Rieder et al. (2023) have devised a caregiver-implemented intervention based on the ESDM in South Africa, aiming to enhance access to early intervention accessibility for autism. Over the course of 12 sessions, a non-specialist guided the caregiver in implementing strategies to increase the child's attentiveness to people, augment communication, establish joint activity routines, and instruct new behaviours. The outcomes were promising, as both caregivers and non-specialists coaches demonstrated improved fidelity scores across the coaching sessions. Also, the child's social communications abilities were improved.

Since embarking on this doctoral project in 2018, research on children with autism in immigrant communities has seen a surge, with numerous several studies being published. Nevertheless, there are research gaps in this sphere. Furthermore, autism in non-Western countries remains underexplored, for instance, in areas such as prevalence estimates, the impact of interventions, and the influence of social and cultural factors on families and caregivers. In broad strokes, research ought to encompass a more diverse array of ethnic and linguistic minority children, given that a majority of participants in studies hail from White and high-SES communities (West et al. 2016).

Research has reported an increased risk of autism in children of immigrants (Schmengler et al. 2021). A crucial research question centers on comprehending the specific risk factors that underlie the connection between parental immigrant

status and the onset of autism in offspring. Multidisciplinary research and collaboration are needed to further evaluate the potential effect of the genetic, nongenetic, and epigenetic factors contributing to the etiology of autism. Various hypotheses have been posited, such as vitamin D deficiency during pregnancy, but further investigation is warranted.

Further research should be geared towards crafting psychometrically valid autism screening and assessment tools that cater for diverse groups, including immigrant children and children in non-Western countries. Additionally, research should strive to formulate a systematic approach to adapting evidence-based interventions that consider the linguistic and cultural backgrounds of families of children with autism in resource-constrained settings.

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