

Autism in preschoolers

Assessment, diagnostic and gender aspects

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Autism in preschoolers
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To my family

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ABSTRACT

Background: Very early assessment of young boys and girls with suspected autism spectrum disorders (ASD) is widely advocated, but knowledge is limited. **Aims:** Evaluate methods used in assessment of young children with suspected ASD, identify possible gender differences in clinical presentation, and examine parent/teacher experiences of the diagnostic process. **Material and methods:** Children (under age 4 years) were recruited after general population screening for ASD in Gothenburg. Different approaches - observation, formal testing, interview, and questionnaire - were used in four sub-studies (I-IV), each relating to 6-20 girls and 20-31 boys. Preschool free-field observation made by an education specialist was compared with structured clinic observation (I). Agreement across clinical first impressions and between such impressions and final comprehensive diagnosis was examined for independent members of a multidisciplinary team (II). Girls and boys were compared as regards diagnosis, developmental profiles and global functioning (III). Parent/teacher experience of assessment was examined (IV). **Results:** Agreement between observation in preschool and clinic was very good. Preschool observation and parent interview showed good agreement with final diagnosis. No clinical presentation gender differences were found, and correlations between results obtained in different developmental areas were strong. Parents and teachers were satisfied with the assessment and diagnostic process and did not regret that they had taken part in it. **Conclusions:** Girls and boys with ASD problems identified before 4 years of age are very similar. Preschool observation should be included in the diagnostic process, multidisciplinary assessments are crucial, and early diagnosis is considered important both by parents and preschool teachers.

Keywords: autism, early diagnosis, gender, preschool, parents, teachers

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SAMMANFATTNING PÅ SVENSKA

Under hela mitt yrkesliv har jag som pedagog intresserat mig för barn med olika utvecklingsavvikelser. Efter flera års tjänstgöring som förskollärare och specialpedagog inom förskola, skola och barn- och ungdomshabilitering, började jag för 12 år sedan att arbeta med neuropsykiatriska utredningar vid Barnneuropsykiatriska kliniken (BNK), Drottning Silvias Barn- och Ungdomssjukhus i Göteborg. Successivt försköts fokus även på kliniken mot förskolebarn. I Sverige går, enligt Skolverkets statistik för år 2012, 83% av 1-5-åriga barn i förskolan. Detta innebär att förskolan är en stor del av barnets liv. I min avhandling står pedagogens roll på kliniken delvis i fokus, framför allt den del som berör kartläggning och samarbete med förskolan.

Avhandlingsarbetet tar sin utgångspunkt i “Tidig Upptäckt, Tidiga insatser” (TUTI, på engelska “Autism Diagnosis and Intervention in the Early life”/AUDIE), ett samarbetsprojekt mellan Barnhälsovården (BHV), Barnneuropsykiatri (BNK) och Barn- och Ungdomshabiliteringen (BUH) i Göteborg. Tidiga insatser kräver tidig upptäckt och därför har screening av språk, kommunikation och autism vid 2,5 års ålder införts vid BHV i Göteborg. Alla barn som faller ut i screeningen eller på annat sätt identifieras med misstanke om neuropsykiatriska utvecklingsavvikelser, remitteras till BNK för utredning. Barn som diagnostiseras erhåller rätt till stöd och remitteras vidare för att få fortsatta insatser vid BUH. Deltagarna i alla delstudierna var flickor och pojkar eller deras föräldrar och lärare rekryterade med utgångspunkt i barngruppen som ingick i TUTI.

Autismspektrumtillstånd (Autism Spectrum Disorder [ASD]) innebär betydande begränsningar gällande förmåga till samspel, kommunikation och lek, samt annorlunda beteende. Förekomsten är ca 1% i totalbefolkningen och ca 0.8% bland förskolebarn. Betydligt fler pojkar än flickor identifieras. Tidigare studier pekar på att det finns skillnader mellan unga flickors och pojkars utvecklingsprofiler, framför allt när det gäller barn med en högre kognitiv nivå. Samtidigt upptäcks flickor ofta senare än pojkar, vilket gör att det teoretiskt kan vara så att det finns en grupp flickor som inte ingått i dessa studiematerial. Detta innebär i sin tur att dessa flickor får tillgång till insatser betydligt senare än pojkar, trots att forskning visar på att tidiga insatser är viktiga för barnets utveckling.

Olika studier har beskrivit vikten av att i neuropsykiatriska utredningar observera små barn i vardagsmiljön, eftersom formella tester inte alltid är tillräckliga för att kartlägga barnets förmågor. Det är därför viktigt att

utveckla instrument och metoder som är avsedda för detta ändamål. Att vara förälder till ett barn med misstänkta utvecklingsavvikelse innebär ofta stora påfrestningar på olika sätt. Detta gör att föräldrarnas situation också måste tas i beaktande i samband med utredning av små barn.

I det första delarbetet (Studie I), undersöktes om man genom att observera barnet i förskolan, (på gruppnivå) får fram samma resultat som om man observerar barnet på kliniken med hjälp av Autism Diagnostic Observation Schedule (ADOS). ADOS är en lekobservation som bedömer samspel, kommunikation, lek och beteende och är ett ofta använt instrument i samband med utredningar av ASD. Genom att i förskolan observera 40 barn (9 flickor, 31 pojkar) vad gäller samma funktionsområden som i ADOS och jämföra resultaten med dem man fått fram vid oberoende ADOS-testning på kliniken, framkom att det endast var inom ett delområde som det fanns en signifikant skillnad, nämligen "initiering av delad uppmärksamhet" som barnet gjorde mera av i förskolan. Resultaten antyder att det i allmänhet går lika bra att identifiera ASD-symptom hos små barn i vardagssituationer i förskolan som vid ADOS-bedömning på kliniken (där dock bilden från förskolan torde ge en mer realistisk bild av barnet).

I det andra delarbetet (Studie II), var syftet att undersöka hur olika bedömares första kliniska intryck stämde överens med den slutliga diagnosen. Trettiofyra barn (6 flickor, 28 pojkar) utreddes av ett multidisciplinärt neuropsykiatriskt team. Resultatet visade på en varierande överensstämmelse mellan olika miljöer/utredningsmoment och slutlig diagnos, samt mellan enskilda personer och slutlig diagnos. De bedömningar som visade bäst överensstämmelse med slutlig diagnos var observationen i förskolan och föräldrintervjun. Minst träffsäker var bedömningen gjord omedelbart efter den första neuropsykologiska testningen. Detta talar för att det fortsatt är viktigt med multidisciplinära utredningar med varierade metoder och stärker även att observationer i förskolan ger viktig information. Den psykologiska testningen i sig är dock nödvändig för att få en säker uppfattning om barnets allmänna utvecklingsnivå, även om man vid själva testtillfället inte alltid får fram tillräckligt underlag för en välgrundad ASD-diagnos.

Jag undersökte även om det fanns några könsskillnader gällande barnens kliniska profiler. Därför jämfördes i studie III alla 20 flickor som deltog i projektet under en viss tid med 20 pojkar som matchades utifrån ålder och utvecklingsnivå. Barnen jämfördes på gruppnivå gällande kommunikativ och social förmåga, motorik, problemlösningsförmåga, beteende, anpassning i vardagen och slutlig diagnos. Resultatet visade inte på några signifikanta skillnader i vårt studiematerial. Detta kan tyda på att det kan vara mindre

skillnader mellan flickor och pojkar än vad man tidigare funnit, eller att det fortfarande finns flickor som inte identifieras genom screening i denna låga ålder (kanske på grund av att deras problem inte känns igen som talande för "autism"). Klart är att det krävs betydligt mera forskning inom detta område.

Slutligen undersöktes hur föräldrarna och förskollärarna upplevde utredningsprocessen, samt kartlades vid vilken ålder barnets problem först uppmärksammats och av vem (Studie IV). Jag skickade ut frågeformulär till 34 barns (8 flickor, 26 pojkar) föräldrar och till barnens förskolor. Jag fann att flertalet föräldrar själva hade uttryckt oro före barnets andra födelsedag. Förskollärarna rapporterade också oro vid ungefär samma ålder. Ingen av föräldrarna ångrade att utredningen genomfördes, och de var genomgående nöjda med utredningsprocessen.

Sammanfattningsvis har jag inte hittat några skillnader mellan flickor och pojkar i vårt material, men resultaten talar för att mer forskning behövs, så att alla barn med svårigheter inom ASD får samma möjlighet till insatser i tidig ålder. Multidisciplinära utredningar av små barn behövs och det är viktigt att se barnet i olika miljöer, dvs. inte bara på kliniken, utan även i barnets förskola. Slutligen visar denna forskning att även om föräldrar inte alltid på eget initiativ söker hjälp tidigt för sina barn, har de ändå en tidig oro och de önskar en tidig utredning av barnet med misstänkta utvecklingsavvikelser.

LIST OF PAPERS

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

- I. Westman Andersson G., Miniscalco C., Johansson U., Gillberg C. (2013). Autism in toddlers: Can observation in preschool yield the same information as autism assessment in a specialised clinic? *The Scientific World Journal*, vol. 2013: Article ID 384745.
- II. Westman Andersson G., Miniscalco C., Gillberg C. (2013). Autism in preschoolers: Does individual clinician's first visit diagnosis agree with final comprehensive diagnosis? *The Scientific World Journal*, vol. 2013: Article ID 716267.
- III. Andersson G.W., Gillberg C., Miniscalco C. (2013). Preschool children with suspected autism spectrum disorders: Do girls and boys have the same profiles? *Research in Developmental Disabilities* 34: 413-422.
- IV. Andersson G.W., Miniscalco C., Gillberg C. (2013). Preschoolers worked up for autism: Parent and teacher experiences of the diagnostic process. (Submitted).

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ABBREVIATIONS

ABA	Applied Behaviour Analysis
ADHD	Attention-Deficit/Hyperactivity Disorder
ADI-R	Autism Diagnostic Interview-Revised
ADOS	Autism Diagnostic Observation Schedule
AHC	Autism Habilitation Centres
ASD	Autism Spectrum Disorder
AUDIE	AUtism Detection and Intervention in Early life
CGAS	Children´s Global Assessment Scale
CHC	Child Health Centre
CNC	Child Neuropsychiatry Clinic
COSMIC	Classroom Observation Schedule to Measure Intentional Communication
DISCO	Diagnostic Interview for Social and COmmunication disorders
DQ	Developmental Quotient
DSM	Diagnostic and Statistical Manual of Mental Disorders
ESSENCE	Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations
GDS	Griffiths´ Developmental Scales
ICF	International Classification of Functioning, Disability and Health
IQ	Intelligence Quotient

JA-OBS	Joint Attention-OBServation
M-CHAT	Modified CHecklist for Autism in Toddlers
PDD	Pervasive Developmental Disorder
PDD-NOS	Pervasive Developmental Disorder Not Otherwise Specified
POC	Playground Observation Checklist
RDLS-III	Reynell Developmental Language Scales III
RRB	Restricted and Repetitive Behaviours
SLP	Speech and Language Pathologist
TEACCH	Treatment and Education of Autistic and Related Communication handicapped CHildren
VABS	Vineland Adaptive Behavior Scales
WPPSI-R	Wechsler Preschool and Primary Scale of Intelligence – Revised

1 INTRODUCTION

1.1 Autism Spectrum Disorder in young children

Autism spectrum disorder (ASD) involves impairing problems with social interaction/communication, and behaviour (American Psychiatric Association, 2013). ASD presents as a clinical problem at various stages of development and intelligence and at various ages. The causes of autism are still a major area of research, even though the influence of genetic mechanisms, maternal, obstetric and other environmental biological factors are generally agreed to be the dominating risk factors (Abrahams & Geschwind, 2008; Coleman & Gillberg, 2012; Dodds et al., 2011; Geschwind & Levitt, 2007).

The prevalence of ASD is about 1% in the general population, but for preschool children a prevalence of 0.8% is now commonly reported (Caronna, Milunsky, & Tager-Flusberg, 2008; Gillberg, 2010; Nygren, Cederlund, et al., 2012). Male to female ratios range from 4-5:1 (Baird et al., 2006; Fernell & Gillberg, 2010; Nicholas, Carpenter, King, Jenner, & Charles, 2009; Nygren, Cederlund, et al., 2012). The description of ASD in this thesis is based on the concept of Pervasive Developmental Disorders (PDD) as outlined in the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV) (American Psychiatric Association, 1994). PDD is synonymous with ASD, which is now the generally accepted term, including in the DSM-5 (American Psychiatric Association, 2013). ASD includes; 1) autistic disorder; 2) Asperger's disorder; 3) childhood disintegrative disorder, and 4) atypical autism (Pervasive Developmental Disorder Not Other Specified/PDD-NOS), even though, in the DSM-5, no special coding for subgroups exist. The DSM-IV criteria for autistic disorder and for atypical autism/PDD-NOS are presented in Table A. Table B presents the criteria for Asperger syndrome (Gillberg and Gillberg 1989, Gillberg 1991), and Table C outlines the new criteria for ASD recently published in the DSM-5.

Table A. Diagnostic criteria for autistic disorder atypical autism/PDD-NOS (DSM-IV)

A. A total of six (or more) items from 1, 2, and 3, with at least two from 1, and one each from 2 and 3:

- 1. Qualitative impairment in social interaction, as manifested by at least two of the following:**
 - a. marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - b. failure to develop peer relationships appropriate to developmental level
 - c. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
 - d. lack of social or emotional reciprocity
- 2. Qualitative impairments in communication as manifested by at least one of the following:**
 - a. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
 - b. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
 - c. stereotyped and repetitive use of language or idiosyncratic language
 - d. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
- 3. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:**
 - a. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - b. apparently inflexible adherence to specific, nonfunctional routines or rituals
 - c. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 - d. persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Atypical autism/Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or when stereotyped behaviour, interests, and activities are present, but the criteria are not met for specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder.

Table B. Diagnostic criteria for Asperger syndrome (Gillberg and Gillberg, 1989/1991)

1. **Severe impairment (extreme egocentricity)** (at least two of the following)
 - a) inability to interact with peers
 - b) lack of desire to interact with peers
 - c) lack of appreciation of social cues
 - d) socially and emotionally inappropriate behaviour
 2. **Narrow interest** (at least one of the following)
 - a) exclusion of other activities
 - b) repetitive adherence
 - c) more rote than meaning
 3. **Repetitive routines** (at least one of the following)
 - a) on self, in aspects of daily life
 - b) on others
 4. **Speech and language peculiarities** (at least three of the following)
 - a) delayed development
 - b) superficially perfect expressive language
 - c) formal, pedantic language
 - d) odd prosody, peculiar voice characteristics
 - e) impairment of comprehension including misinterpretations of literal/implied meanings
 5. **Non-verbal communication problems** (at least three of the following)
 - a) limited use of gestures
 - b) clumsy/gauche body language
 - c) limited facial expression
 - d) inappropriate expression
 - e) peculiar, stiff gaze
 6. **Motor clumsiness**
 - a) poor performance on neuro-developmental examination
-

Table C(1). Diagnostic criteria for ASD (DSM-5)

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity: Severity is based on social communication impairments and restricted, repetitive patterns of behaviour.

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

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

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

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Table C(2). Severity levels, DSM-5

Severity level	Social communication	Restricted, repetitive behaviours
Level 3 Requiring very substantial support	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches.	Inflexibility of behaviour, extreme difficulty coping with change, or other restricted/repetitive behaviours markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.
Level 2 Requiring substantial support	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.	Inflexibility of behaviour, difficulty coping with change, or other restricted/repetitive behaviours appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.
Level 1 Requiring support	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.	Inflexibility of behaviour causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

Although the specific symptom criteria for ASD must be met for a diagnosis to be made, there is still a variety of symptoms in different children (Fernell et al., 2010). Common early symptoms are problems with; eye-contact, response to name, reactions to sensory stimuli, joint attention (particularly self-initiated joint attention), social smile, shared enjoyment, verbal- and non-verbal communication, not playing like other children, including unusual use of toys. There are also restricted and repetitive behaviours (RRB), feeding and sleeping problems (Barnevik Olsson, Carlsson, Westerlund, Gillberg, & Fernell, 2013; Coleman & Gillberg, 2012; Yates & Couteur, 2013). One of the most common signs reported by parents is delayed onset of expressive language (Miniscalco, Nygren, Hagberg, Kadesjo, & Gillberg, 2006; Mitchell et al., 2006). Children with ASD are suggested to have better expressive than comprehensive language skills (Miniscalco, Fränberg, Schachinger-Lorentzon, & Gillberg, 2012). Many children with ASD express single words at age 1-2 years and then stop using them (Coleman & Gillberg, 2012). Long-

term longitudinal research has shown that the majority diagnosed with ASD in childhood, had poor outcome later in life (Billstedt, Gillberg, & Gillberg, 2005; Cederlund, Hagberg, Billstedt, Gillberg, & Gillberg, 2008), suggesting that ASD often infers lifelong disability.

Research and clinical experience suggest that young preschool children show great symptom variation, such that at early stages it is not always possible to identify it as a specific diagnosis such as ASD or another of the childhood diagnoses in the DSM. These variations of problems have been reconceptualised under the umbrella term of Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations (ESSENCE), comprising all kinds of early developmental impairments in very young children. ESSENCE are signalled by problems in a) general development; b) communication-language; c) social inter-relatedness; d) motor coordination; e) attention; f) activity; g) “general” behaviour; h) mood, and/or i) sleep. Major problems in at least one of these areas before 5(-6) years of age, usually indicate significant problems in the same or other ESSENCE/developmental areas several years later (Gillberg, 2010). For instance, a Swedish study showed that approximately 60% of children who screened and tested positive for language disorder at age 30 months, met criteria for ASD or/and Attention-Deficit/Hyperactivity Disorder (ADHD) at follow-up five years later (Hagberg, Miniscalco, & Gillberg, 2010; C. Miniscalco et al., 2006). This suggests that it is important to identify children in early ages so as to be able to provide interventions, even if a specific diagnosis cannot be established at first consultation.

1.2 Children with ASD in Swedish preschools

In Sweden, the vast majority of children aged 1-5 years attend preschool. The preschool’s primary aim is to provide a basis for the first part of children’s learning. The number of children in ordinary Swedish preschools varies between about 15-30 (higher and lower numbers may occur) and the number of teachers (staff with other education included) was approximately one per five children according to The Swedish National Agency for Education (2012). The Swedish School Act states that children in need of extra developmental support must be given the support that their needs require, and the principal of the preschool is responsible for such support (SFS 2010:800). However, there is clearly variation in how the support is provided in different preschools and for individual children.

Clinical experience as regards ASD in Swedish preschools suggests that affected children have problems adapting to daily routines and transitions if they do not receive special help with structure and predictability. There are many children in each group and the preschool setting involves a lot of auditory and visual stimuli, which is generally difficult for the child with ASD to sort out without extra support. This in itself makes unsupported preschool attendance a huge challenge for many children with ASD.

1.3 Diagnostic instruments for ASD

Early identification of any child's need for extra support is essential, meaning that valid assessment tools and methods are needed. To enable early detection, ASD screening instruments and programmes have been studied and used in health care centres within and outside Sweden. One such programme was recently introduced in Gothenburg, Sweden (Nygren, Sandberg, et al., 2012), and this is further presented in chapter 3 in this thesis.

The DSM-IV and DSM-5 are diagnostic manuals used for standard criteria for classification of PDD/ASD and other disorders. To arrive at valid diagnoses according to these classification systems, instruments with potential to elicit adequate information are needed.

Diagnostic evaluations of young children with suspected ASD are recommended to comprise assessments of; 1) developmental level; 2) social interaction skills; 3) restricted interests and repetitive behaviours/RRB, and 4) adaptive behaviour. No single diagnostic instrument can establish the diagnosis and comprehensive clinical judgment by expert clinicians is considered the gold standard for diagnosis (Charman & Baird, 2002; Klin, Lang, Cicchetti, & Volkmar, 2000; Steiner, Goldsmith, Snow, & Chawarska, 2012). Moreover, this suggests that multidisciplinary assessments are important, including interviews with caregivers, free-field observations and formal structured tests (Huerta & Lord, 2012).

For young preschool children with suspected ESSENCE problems, there is a need for psychometrically sound methods of observations in everyday situations. This has been specifically highlighted in a review of "diagnosis of ASD" in young preschoolers (Charman & Baird, 2002). In addition, the parent interview is underscored as very important for eliciting information about the child's abilities and problems (Wing, Leekam, Libby, Gould, & Larcombe, 2002). The variable problem profile described under ESSENCE is another argument for the importance of multidisciplinary assessment teams and tools for identification of these problems, which is also in line with a

newly published report from the Swedish Council on Health Technology Assessment, in which further development of diagnostic tools was suggested to be important (Swedish Council on Health Technology Assessment, 2012).

For ASD-observations in clinical settings, one of the most widely advertised and used tool is the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2000). The ADOS is a standardised, semi-structured instrument, shown to be valid for a clinical diagnosis of autism (Gotham, Risi, Pickles, & Lord, 2007). The first edition of the ADOS (used in the studies included in this thesis) consists of four different modules, corresponding to the level of expressive language. Module 1 is used for young, non-verbal children, module 2 for young children with phrase speech, module 3 for older children with fluent speech, and module 4 for verbally fluent adolescents and adults. Specially trained professionals make observations of the child's communication, social interaction, play and imagination, and stereotyped behaviours/interests using structured activities and materials. During the test (the observation part which takes about 30-50 minutes); one examiner interacts with the child and (usually) another professional observes the child during the test. The examiner and the observer, score the child's performance together after the ADOS observation, according to the manual. An algorithm is used and the scoring result provides a cut-off (classification) for diagnosis of ASD.

A revision of the ADOS has recently been made with a view to improving diagnostic validity, ADOS Revision (ADOS-R) (Gotham, Risi, Pickles, & Lord, 2007). The Autism Diagnostic Observation Schedule, Second edition (ADOS-2) was released in 2012 (www.ados2.com). The ADOS-2 has a new algorithm with fewer items, selected for the best possible diagnostic markers, and module 1 and 2 are further split into language- and age cells.

As has already been mentioned, the majority of 1-5-year-olds in Sweden attend preschool, making the preschool setting a very large part of their everyday environment. Clinical experience suggests that observation of the child in the "free-field" preschool environment often provides very important information about the child in the diagnostic process, but there is little in the way of actual research comparing preschool free-field observation with clinical structured assessment. There is therefore a need for development and refinement of preschool observation tools. Two instruments recently reported to have potential for "free-field" ASD assessments of young children are the Classroom Observation Schedule to Measure Intentional Communication (COSMIC) (Pasco, Gordon, Howlin, & Charman, 2008) and Playground Observation Checklist (POC) (Ingram, Mayes, Troxell, & Calhoun, 2007).

However, the participants in the COSMIC- and POC studies were “relatively old” (4-11 years of age) and all had been clinically diagnosed with autism before the studies were performed.

The Diagnostic Interview for Social and Communication disorders (DISCO) (Wing et al., 2002) is a semi-structured interview intended to collect information from parents and takes about 2-4 hours to complete. The DISCO is designed for obtaining systematic information regarding development and behaviours from birth until current time, to allow classification of ASD in accordance with different diagnostic systems. Another frequently used semi-structured interview with caregivers is the Autism Diagnostic Interview-Revised (ADI-R) (Lord, Rutter, & Le Couteur, 1994). However, ADI-R was not used in the studies included in this thesis, mainly because it elicits less information about ESSENCE than the DISCO, and it is equally time-consuming.

To finalise the diagnosis, many factors need to be taken into account. Due to the high degree of variation as regards phenotypic ASD presentation, developmental level and chronological age etc, diagnosing young children is often a complex process. As already outlined above, the overall clinical impression by experienced clinicians is still considered the gold standard for diagnosis, which in turn requires good knowledge about children’s typical development (Charman & Baird, 2002; Steiner et al., 2012).

There are many more boys than girls in standardisation samples for ASD diagnostic-instruments. This has to be considered as a possible bias in the reported females to male ratio in ASD (Rivet & Matson, 2011) and points to the importance of developing instruments separately tested in both genders.

The Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) was released in May 2013 (American Psychiatric Association, 2013). The four separate disorders in the DSM-IV have been put under one ASD umbrella in DSM-5. ASD symptoms have to be shown from early childhood, even if not noted until later in life. There are also major changes in the symptom criteria. In the DSM-IV, there is symptom division into three domains; 1) deficits in social reciprocity; 2) deficits in communication, and 3) presence of restricted, repetitive behaviours and interests. In the DSM-5 there are only two domains; 1) social communication/social interaction and 2) restricted, repetitive behaviours and interests (Lord & Jones, 2012; Wing, Gould, & Gillberg, 2011). Also, perceptual abnormalities - not specifically listed in the DSM-IV algorithm - are included as a separate “diagnosis-generating” symptom in the DSM-5.

The criteria are in addition formulated to be applied to all ages. For a comparison of the DSM-IV and DSM-5 criteria for autism/ASD, please refer to Tables A and C.

1.4 ASD and gender

There is a reported much raised male:female ratio in ASD, which has been given more and more attention in research over the last years. In addition, girls appear to be diagnosed later in life than boys (Giarelli et al., 2010). However, a newly published study suggested that the average age of parent's first concerns over their child's development was younger for girls than for boys (Horovitz, Matson, Turygin, & Beighley, 2012). The researchers discussed a number of possible explanations for the findings, such as the possibility that there is an earlier onset of ASD symptoms and developmental delay in girls identified in early years than in boys. An alternative explanation could be that only those girls with the most severe form of ASD are recognised at all in the early preschool years and that compared to other girls they stand out as so abnormal that they are recognised very early. Boys with severe autism may not be as so extremely abnormal compared with other boys until they are a few-several months older.

Differences in female and male symptoms have been suggested to be important. It has previously been suggested that girls with ASD who are not intellectual disabled, appear to have better social skills (at least superficially) in the early years, but later on their problems become more obvious and they are therefore diagnosed later (Kopp & Gillberg, 1992; McLennan, Lord, & Schopler, 1993). This has been confirmed in more recent studies (Dworzynski, Ronald, Bolton, & Happe, 2012; Giarelli et al., 2010). There are biological differences making girls genetically more protected from expressing the most striking phenotypical symptoms of ASD (Constantino & Charman, 2012).

There is insufficient knowledge as regards girls with ASD in the very early years, but some researchers have suggested that girls with ASD, aged 4 years or below, have greater communication problems than boys, and that boys have more RRB than girls (Carter et al., 2007; Hartley & Sikora, 2009; Sipes, Matson, Worley, & Kozlowski, 2011; Werling & Geschwind, 2013). These differences have been found to be stable across the age range of 3-18 years (Mandy et al., 2012) and the researchers speculated that less severe school problems in girls could be one explanation why they are being missed. However, a Swedish study of 100 girls clinically referred for suspected ASD/ADHD (3-18 years of age) showed high levels of school dysfunction

and almost every second girl had been exposed to bullying (Kopp, Kelly, & Gillberg, 2010). Another study focusing on psychiatric problems did not show any significant gender differences in a study sample of children aged 4-16 years (Worley & Matson, 2011). Thus over the next several years, a big challenge for health care services will be the early identification of girls (and boys) with suspected ASD, not showing the “expected” symptoms of ASD.

Gender differences are actually well established in typically developing children. Previous studies suggest that girls under one year of age, show stronger social orientation and interest in human faces (Lutchmaya & Baron-Cohen, 2002). They also are considered as showing more eye contact (Lutchmaya, Baron-Cohen, & Raggatt, 2002) and imitation skills (Nagy, Kompagne, Orvos, & Pal, 2007) than same-aged boys. Among preschool children, especially at 3-4 years of age, girls are reported to have more social play than boys (Barbu, Cabanes, & Le Maner-Idrissi, 2011).

ASD is by some researchers considered as an extreme of the typical brain profile, where females are suggested to have better empathising skills than males, and males are better in systemising than women (Baron-Cohen, 2010). The question arises as to whether gender differences observed in ASD might be similar to those observed in the general population (Thompson, Caruso, & Ellerbeck, 2003).

Gender differences in the general population have been discussed in a broader perspective than only as regards differences between the biological sexes in boys and girls. The Australian sociologist Raewyn Connell is defining gender as “*the structure of social relations that centres on the reproductive arena, and the set of practices that bring reproductive distinctions between bodies into social processes*” (p 11; Connell, 2009), that is, the way society relates to the human body and the consequences this brings to our daily lives. Moreover, this is influenced by cultural and socioeconomical factors.

This is also discussed with an ASD view (Goldman, 2013), highlighting that even if the lower sex ratio of girls in ASD could be biologically based, one also has to consider the process of socialisation due to the biological sex, where especially verbal (less cognitively impaired) children with ASD could have abilities to conform to at least some of the sex-based behavioural expectations in their everyday environment. This would contrast with the severely cognitive impaired children where the typical gender behaviours are not being incorporated to the same extent.

1.5 Parents' first concerns and stress

Parents' first concerns about children later diagnosed as ASD often start very early and are very common during the child's second year, even if earlier and later concerns have also been reported (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011; Ozonoff et al., 2009; Ryan & Salisbury, 2012; Siklos & Kerns, 2007; Zwaigenbaum, Bryson, & Garon, 2013). Despite the lower number of girls diagnosed with ASD, parent's first concerns for girls diagnosed with ASD have been reported to be earlier than for boys, where an earlier onset of ASD symptoms in girls than in boys has been discussed as a possible explanation (Horovitz et al., 2012); for alternative explanations, see above.

Parents of young children with ASD are reported to have a very stressed situation related to the child's problems (Estes et al., 2013; Pottie & Ingram, 2008; Schieve, Blumberg, Rice, Visser, & Boyle, 2007), and they are also suggested to show higher levels of stress compared to parents of children with developmental delay without ASD. The stress includes concerns about the child's behaviour problems, child raising problems, and financial strains. There are also high rates of divorce reported among these parents (Karst & Van Hecke, 2012). Previous studies have shown that these strained and problematic situations occur regardless of the severity of the child's ASD (Pottie & Ingram, 2008). Parental stress has also been shown to have a negative impact on interventions targeting child's problems (Osborne, McHugh, Saunders, & Reed, 2008).

1.6 Parent and teacher experiences of the diagnostic process

Since parents - under typical circumstances - are the most important persons in the child's first years, the parent situation has to be taken into account and protected to benefit the whole family's well-being. There is a need for more research as regards parents' experiences in the diagnostic process of ASD. Previous studies have suggested that parents who had to wait longer for the diagnosis were less satisfied with the diagnostic process than those who received an earlier diagnosis (Howlin & Moorf, 1997). In addition, both clinical and research experience suggest that many parents have been stressed by "wait and see attitudes" and have expressed frustration by not receiving answers and help as regards their child's problems (Mansell & Morris, 2004; Sansosti, Lavik, & Sansosti, 2012).

Parents are reported to prefer a quick, structured diagnostic process containing adequate information (Abbott, Bernard, & Forge, 2013; Chamak et al., 2011; Osborne & Reed, 2008; Reed & Osborne, 2012). Unfortunately many parents have reported the opposite, that the time period of the diagnostic process has been too long and the information during the process too limited (Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010). Frustration connected to frequency of visits to different doctors and other specialists has been expressed by parents, and this is also connected with longer waiting time for diagnosis and economic factors, where parents have to pay for visits in health care, absence from work, travel costs, etc. (Goin-Kochel, Mackintosh, & Myers, 2006).

All these findings suggest that better routines needs to be developed to increase parents' participation during the process. This is in line with International Classification of Functioning, Disability and Health (ICF) (WHO, 2001), which is meant to provide a common language and a description of health and health related states in everyday life (Björck-Åkesson et al., 2010; Kohler et al., 2013). Individualisation in interventions and keeping the family context in focus are suggested to be important for positive outcomes in family functioning (Ylvén, Björck-Åkesson, & Granlund, 2006) and a well functioning family could benefit the child's positive development. The ICF is used in habilitation centres in Sweden among other countries, in the intervention process for children and their families who are in the target group for habilitation.

We have not been able to find any research documenting the perceptions of teachers in relation to the diagnostic process in ASD.

1.7 Interventions and family support after diagnosis

In Sweden, most children diagnosed with ASD are receiving interventions by autism habilitation centres, often in collaboration with the preschool/school. Early interventions for children with ASD have been suggested to be important for a positive development (Dawson et al., 2010; Eikeseth, 2009; Föreningen Sveriges Habiliteringschefer, 2012; Myers & Johnson, 2007; Rogers & Vismara, 2008). New methods for ASD intervention is constantly evolving and a subject for research. Treatment and Education of Autistic and Related Communication handicapped CHildren (TEACCH) has been widely used over the years in the practice for autism. Meta-analyses have prevented limited support for TEACCH but there are currently very few studies on its

impact on ASD (Virues-Ortega, Julio, & Pastor-Barriuso, 2013). Applied Behaviour Analysis (ABA) is suggested to (so far) have more support for positive impact on children with ASD problems (Eldevik et al., 2009) than other interventions. However, a recent study from Stockholm, Sweden did not find any supporting link between intensive intervention (compared to less intensive intervention) and adaptive capacities after two years of longitudinal follow-up (Fernell et al., 2011). A higher cognitive level has, in other studies, been suggested to have a positive impact in terms of greater adaptive skills in children with ASD (Kanne et al., 2011).

2 AIM

The main aim of the present thesis was to focus on the assessment of preschool children with suspected ASD. The specific aims were to;

1. study whether or not ASD assessment in real-life free-field preschool settings yields the same information as does assessment in a structured ASD specialised clinic setting;
2. provide guidance regarding the extent of neuropsychiatric assessment needed in young children worked up for suspected ASD;
3. study similarities and differences between young preschool girls and boys with suspected ASD;
4. study the experiences of parents and teachers regarding early neuropsychiatric assessment of young children with suspected ASD.

3 METHODS

3.1 The AUDIE collaboration project in Gothenburg

The Autism Detection and Intervention in Early life (AUDIE project) is a collaborative effort across the Child Neuropsychiatry Clinic (CNC), Child Health Care (CHC), and Autism Habilitation Centres (AHC) in Gothenburg. The primary aim of this project has been to evaluate effective routines for early detection, diagnostic assessment, and intervention for young children with ASD. All 2.5-year old children in the general population were screened for ASD at the CHC by nurses using the Modified Checklist for Autism in Toddlers (M-CHAT) (Robins, Fein, Barton, & Green, 2001) and a joint attention observation (JA-OBS) (Nygren, Sandberg, et al., 2012). If suspicion of ASD was raised, a second examination by a doctor together with the nurse was made. If the ASD suspicion then remained, the child was referred to the CNC for diagnostic assessment (see below). Children diagnosed with ASD were then further referred to the AHC for early intervention.

There was also a CHC screening for language problems, and children who failed the language- but not the ASD-screening were referred for auditory and language assessment. Some children were suspected of ASD in connection with these assessments and they were also referred to the CNC.

After the AUDIE project was completed, the screening programme has continued and is currently routine in Gothenburg. The number of births in Gothenburg has increased over the last years from about 6000/year at the time when the project was introduced, to about 7000 in 2012. The screening identified about 60 children/year in 2010, and the number of preschool children referred to the CNC in 2012 was more than 80. Incidentally, the number of children under age 4 years referred for ASD suspicion to the CNC in 2005, a few years before the AUDIE project started, was two.

3.2 Participants

The participants in the four studies were recruited from the general population of children in Gothenburg, in the framework of the AUDIE project. All children were under 4 years of age at the time of referral to the CNC. An overview of the participants in the four studies is presented in Figure 1.

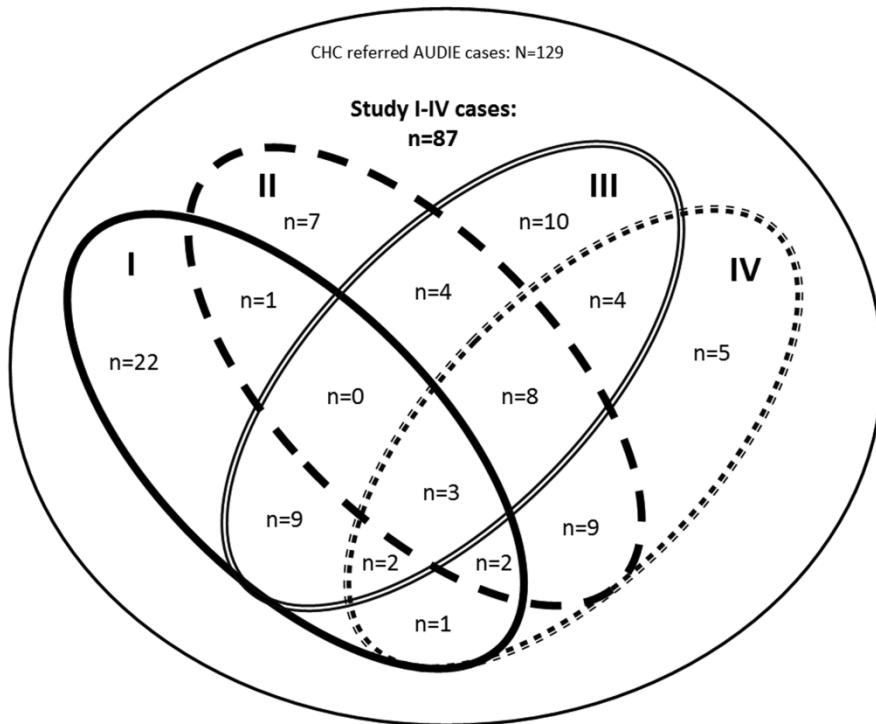


Figure 1. The overlap of the four studies shows the distribution of all participants.

Study I (Preschool study): Forty children (9 girls, 31 boys), 29-51 months, of age were included. They were consecutively selected and were the first forty children included in the CNC cohort of the AUDIE project. There was no attrition in this study.

Study II (Clinical judgment study): Thirty-four children (6 girls, 28 boys), 24-46 months of age, were consecutively selected from the CNC AUDIE-cohort during a limited time-period (because of specific requirements of the study design, see below). Forty-two children had originally been targeted, but eight had to be excluded because data were missing.

Study III (Gender study): All twenty girls included in the CNC AUDIE-cohort were matched by age and developmental age with 20 boys who were also included from the CNC AUDIE-cohort. (The matching procedure is further presented below).

Study IV (Parent and teacher study): Thirty-four children (8 girls, 26 boys) from the CNC AUDIE-cohort were included in this study. All parents who had agreed to participate in the AUDIE project during the latter part of the project were selected for inclusion. Fifty families were initially targeted, but 12 were excluded because neither parent was able to read Swedish, and four further families were excluded because their child did not receive a diagnosis of ASD or other ESSENCE problems after full assessment.

3.3 Clinical neuropsychiatric examination

All children in the four studies were assessed and diagnosed by a multidisciplinary team consisting of medical doctor, psychologist, speech and language pathologist (SLP), and education specialist. After all the assessments were completed, the results were presented to the parents at a conference for conclusions. In addition, a diagnostic information sharing conference with representatives from the preschool and habilitation centre was held.

All children included in the four studies underwent the assessments as presented in the following (3.3.1-3.3.7). Methods especially designed for the research process are described more in detail (3.3.8-3.3.11). Different approaches were used in the assessments; 1) observation; 2) formal testing; 3) interview, and 4) questionnaire. One of the four studies included a longitudinal approach.

3.3.1 Medical, psychiatric and neurological examination

A medical/developmental/psychiatric history taken from the parents was carried out by a medical doctor. The doctor observed and interacted with the child, and a neurological and brief neuropsychiatric examination of the child was made.

3.3.2 Measurement of developmental quotient and adaptive skills

Developmental quotient (DQ) was assessed by a psychologist using the Griffiths' Developmental scales (GDS) (Alin-Åkerman & Nordberg, 1991), and, whenever appropriate, the Wechsler Preschool and Primary Scale of Intelligence – Revised (WPPSI-R) (Wechsler, 2005). The Vineland Adaptive Behavior Scales (VABS) (Sparrow, Balla, & Cicchetti, 1984) was used to evaluate adaptive skills in everyday situations.

3.3.3 Language measurement

Language was evaluated by a speech and language pathologist (SLP), using the Reynell Developmental Language Scales III (RDLS-III) (Arvidsson & Köröndi, 2011; Edwards et al., 1997) and the MacArthur Communicative Development Inventory (Eriksson & Berglund, 2002; Fenson et al., 1994). The Swedish version of the RDLS-III has norms only for the comprehension part and therefore we only administered this part. The results of the RDLS-III receptive, contain 62 test items sorted into 10 different domains, i.e. from comprehension of single words to sentences of increasing complexity with a maximum score of 62. Language production was also assessed with different tests. In the present context five levels were used to categorise the child's expressive language level; a) no words at all; b) a few single words; c) a few communicative sentences; d) talks a great deal, mostly echolalia, and e) talks a great deal, mostly in communicative manner.

3.3.4 Parent interview

The DISCO-11 (Nygren et al., 2009; Wing et al., 2002) was used at interviews with at least one parent by a DISCO trained examiner in the assessment team. The DISCO is further described in the Introduction (page 9).

3.3.5 Observation in clinic setting

The Autism Diagnostic Observation Schedule-Generic (ADOS) (Lord et al., 2000) was used for assessment of the child's communication, reciprocal social interaction, play, and behaviour in the clinic setting. Two ADOS trained team members (psychologist, SLP, or education specialist) performed the ADOS with the child at the clinic with at least one parent present in the room. One test manager played with the child and one observer documented the procedure (30-40 minutes) as previously described in the Introduction (page 8). Video-recordings were made for interrater reliability study and for use in connection with the scoring procedure if necessary. Modules 1 or 2 of the ADOS were used (depending on child's speech level), which involves activities adjusted for very young children.

The ADOS Severity scale was used for measurement of severity of ASD symptoms (1-10) according to the ADOS-R (de Bildt et al., 2011; Gotham, Pickles, & Lord, 2009). ADOS classification for "no ASD" = severity level 1-3; for ASD (under the level of autistic syndrome) = severity level 4-5, and for autistic syndrome = severity level 6-10.

3.3.6 Preschool observation

Children attending a preschool were observed by an education specialist from the assessment team, in group activities and free play for about one hour. Children not in preschool were observed in their home, with at least one parent and any siblings present. In addition the preschool teachers were interviewed about the child's abilities in everyday situations in general. The observations were done by using a specially designed protocol (Appendix 1& 2) - based on the symptom areas of the ADOS - while the teachers/parents were interacting with the children as they normally would. The children were attending ordinary preschools with groups of 15-30 children.

3.3.7 Conferences of conclusions and information

Clinical consensus diagnosis conference: After all observations and tests were completed independently (and all the specific results of these assessments had been filed and sealed before any discussion across professionals occurred), all team members made conjoint consensus clinical diagnoses according to DSM-IV-criteria, and conjointly rated the general social and psychiatric functioning of the children using the Children's Global Assessment Scale (CGAS) (Schorre & Vandvik, 2004; Shaffer et al., 1983). The CGAS scores range from 1 to 100 where the highest level (scores above 70) indicate a range from slight impairment to superior functioning and the lowest level (scores below 10) indicate need for constant supervision.

Conclusion and information conferences: A conference for conclusion was held with the parents, where at least three of the assessment team members were present. The parents received information about the test results and the final clinical diagnosis. They were also invited to have a referral to the habilitation centre for their child. Approximately one month later (if the parents agreed), an information conference was held with two of the assessment team members, the parents, representatives from the child's preschool, and the habilitation centre. At this conference the diagnosis and the child's need for support were discussed.

3.3.8 Preschool study – observation and reliability procedure

In the observation procedure of the children included in the Preschool study (9 girls, 31 boys), the two education specialists performed the ADOS assessments at the clinic and in the preschool/child's home. To avoid bias,

examiner 1 (the author) performed the preschool observation of child 1 who was then (blindly) assessed by examiner 2 using the ADOS in the clinic together with another ADOS-trained observer. Examiner 2 then performed the preschool observation of child 2 who was (blindly) ADOS assessed by examiner 1 in the clinic. All ADOS clinical assessments were scored by the examiner and the observer together.

Interrater reliability for the two education specialists (examiner 1 and 2) in the preschool observations was calculated for scores on all the variables in the ADOS algorithm, used in the preschool observation results for 10 children included in the larger AUDIE-population, but not in the Preschool study. The two examiners observed and scored the same child at the same time at preschool, not talking to each other about what they observed. For interrater reliability measures of the clinical ADOS examination, another 10 children were blindly examined using videotapes of the ADOS assessment. Examiner 1 examined 5 videotaped observations, performed “live” by examiner 2, and examiner 2 examined 5 videotaped observations performed by examiner 1. For the items included in the preschool observation, the percent agreement ranged from 83% - 94% and weighted kappa statistics ranged from 0.82 – 0.93. For the ADOS, percent agreement ranged from 88% - 100% and weighted kappa ranged from 0.85 – 1.0. Interrater reliability was therefore considered good to very good (Table 1).

Table 1. Results of interrater reliability measurements of ADOS (n = 10) and Preschool observation (n = 10). Calculated as percent agreement (point-by-point method) and Weighted kappa

	Interrater measurement	
ADOS	Percent agreement	Weighted kappa
Communication	88	0.85
Reciprocal social interaction	93	0.91
Play and imagination	100	1.0
Stereotyped behaviours and restricted interests	90	0.89
Preschool observation		
Communication	90	0.89
Reciprocal social interaction	94	0.93
Play and imagination	88	0.82
Stereotyped behaviors, and restricted interests	83	0.82

3.3.9 Clinical judgment study – procedure

All the assessments at the clinic and in the preschool/home were performed independently of each other and the clinicians were blind to any information obtained at other evaluations of the child at the preschool or CNC. A coding sheet was designed (by the author) and distributed to all clinicians participating (one sheet per child per clinician). On this sheet each examiner's clinical judgment was written at the end of the child's first visit to that clinician (who had had been instructed at repeated conferences not to discuss anything about the patient with anybody else in the clinic), and before formal summaries of the assessments were made. The ASD options on the coding sheet were (1) ASD; (2) ASD probable or possible; or (3) no ASD. The examiner could also make other comments in a separate box on the coding sheet regarding the child's problem. Each coding sheet was then put in an envelope, sealed and stored away, and was not opened until all the individual assessments, and the diagnostic process had been completed.

3.3.10 Gender study – matching of girls and boys

All 20 consecutive girls, whose parents approved participation in the AUDIE project, were matched with 20 boys from the same cohort. They were matched for chronological age (± 5 months) and developmental quotient (DQ) level (<50; 50-59; 60-69; 70-79; >80). The total number of girls in the AUDIE project was small, and due to that, no matching was done for ethnicity, parental education level etc.

3.3.11 Parent and teacher study – questionnaires

All parents and preschool teachers of the 34 children included in this study received a questionnaire, after the diagnostic process and the conference with representatives from preschool and habilitation were completed (Appendix 3&4). Thirty-four parents and 29 teachers responded to the questionnaires, but a few of these did not answer all the questions. The questionnaires included questions about the time of first concerns about the child, parent/teacher perception about early diagnosis and about the diagnostic process at the CNC. In order to examine whether the parents opinion had changed one year after the diagnosis had been made, another questionnaire, including the same items plus three further questions, was sent to the parents when one year had expired after the first questionnaire screening. Twenty-five parents responded to both questionnaires. Because of the relatively frequent changes as regards teaching staff, and children moving to another preschool, the teachers only received the questionnaire the first time. Comparisons across parent and teacher responses were made for four questions that were identical on both versions of the questionnaire.

3.4 Statistical methods

Continuous variables were described with means, standard deviations (SD), medians, and ranges. Categorical variables were described with number and percentages.

Due to the small number of participants in the four studies, non-parametric statistics were used throughout.

For comparison within children, Wilcoxon signed rank test was used for continuous variables (study I) and Sign test for ordered categorical and dichotomous variables (study I, II and IV).

Sensitivity and specificity with 95% confidence interval were analysed for each category assessor with final clinical diagnosis as the golden standard in study II.

Percent agreement and Weighted kappa (with 95% confidence interval) was used in analysis of agreement for ordered categorical variables (study I, II and IV). The kappa statistic was used in analysis of agreement for dichotomous variables in study IV.

For comparison between two groups, Fisher's exact test was used for dichotomous variables, Mantel-Haenszel chi-square exact test for ordered categorical variables, and Mann-Whitney U-test for continuous variables (study IV).

Spearman rank correlation coefficient was used for correlation analysis in studies III and IV.

All significance tests were two-tailed and conducted at the 0.05 significance level.

There were some methodological challenges in study I stemming from the fact that 24 children were coded using module 1, and 16 were coded using module 2, so we analysed the data in different ways to ensure that conclusions would not be influenced by our handling of the data across instruments. Specifically, ADOS module 1 and 2 contain 11 common variables. In addition, in module 1 there are another six variables unrelated to the common ones, and in module 2, there are five such unrelated variables. The material was therefore analysed in three different stages:

1. Comparison of the overall results of each domain of module 1 and 2, and the combined result of communication and social interaction, which, in the ADOS, gives cut-off for ASD-diagnosis. Thus, no attempt was made to correct for differences in the modules.
2. To get a larger number of comparable variables, the summarised results of only the common variables for both module 1 and 2 were calculated. This score is referred to as the "collapsed global" score in study I. Children were compared also on this score from the preschool observation and from the ADOS assessment at the clinic.
3. Each variable within each domain was analysed.

3.5 Ethics

The study was approved by the Regional Ethics Committee in Gothenburg, Sweden. Informed consent was obtained from at least one of the parents/responsible carers in each case.

4 RESULTS

4.1 Study I - Preschool

Data from both module 1 and module 2 in ADOS are presented in Table 2 for all children, divided into four domains; (1) *Communication*, (2) *Reciprocal Social Interaction*, (3) *Play and Imagination* and (4) *Stereotyped Behaviours and Restricted Interests*. For the 40 children included in this study, the ADOS clinical and the preschool observation both showed a mean result of more than 12 points in combined total score for communication and reciprocal social interaction, indicating a diagnosis of autism according to ADOS algorithm. Sign test comparisons of the variables rated in preschool and corresponding items in the clinic, showed a significant difference only with regard to spontaneous initiation of joint attention ($p=.01$). For all other variables there was good agreement according to sign test, percentage agreement, and weighted kappa across the two methods and settings. In some cases the score was somewhat higher (though not significantly) in the clinic, and in some cases it was higher in the preschool observation.

Table 2. Agreement between ADOS and preschool observation findings (module 1, n=24, module 2, n=16). Number with higher score at each type of observation is described

DOMAINS	N	Agreement	ADOS Higher	Preschool Higher	p-value	Weighted Kappa
Communication						
Frequency of vocalisation directed to others	24	17 (71%)	4 (17%)	3 (13%)	1.0000	0.33
Amount of social overtures	16	10 (63%)	5 (31%)	1 (6.3%)	0.2188	0.35
Stereotyped/idiosyncratic use of words or phrases	40	28 (70%)	4 (10%)	8 (20%)	0.3877	0.43
Use of others body to communicate	24	13 (54%)	7 (29%)	4 (17%)	0.5488	0.26
Conversation	16	9 (56%)	2 (13%)	5 (31%)	0.4531	0.38
Pointing	40	24 (60%)	10 (25%)	6 (15%)	0.4545	0.52
Gestures	40	23 (58%)	9 (23%)	8 (20%)	1.0000	0.44
Reciprocal social interaction						
Unusual eye contact	40	32 (80%)	4 (10%)	4 (10%)	1.0000	0.56
Facial expressions directed to others	40	25 (63%)	6 (15%)	9 (23%)	0.6072	0.53
Shared enjoyment in interaction	24	12 (50%)	3 (13%)	9 (38%)	0.1460	0.21
Showing	24	15 (63%)	6 (25%)	3 (13%)	0.5078	0.41
Spontaneous initiation of joint attention	40	26 (65%)	12 (30%)	2 (5.0%)	0.0129	0.57
Response to joint attention	24	13 (54%)	4 (17%)	7 (29%)	0.5488	0.42
Quality of social overtures	40	25 (63%)	4 (10%)	11 (28%)	0.1185	0.47
Quality of social response	16	7 (44%)	2 (13%)	7 (44%)	0.1797	-0.07
Amount of reciprocal social communication	16	10 (63%)	3 (19%)	3 (19%)	1.0000	0.33
Overall quality of rapport	16	8 (50%)	3 (19%)	5 (31%)	0.7266	0.35
Play and imagination						
Functional play with objects	24	15 (63%)	4 (17%)	5 (21%)	1.0000	0.43
Imagination/creativity	40	26 (65%)	8 (20%)	6 (15%)	0.7905	0.57
Stereotyped behaviours and restricted interests						
Unusual sensory interest in play material/person	40	30 (75%)	6 (15%)	4 (10%)	0.7539	0.14
Hand and finger and other complex mannerism	40	26 (65%)	6 (15%)	8 (20%)	0.7905	0.51
Unusual repetitive interests or stereotyped behaviours	40	22 (55%)	8 (20%)	10 (25%)	0.8145	0.42
The comparison data is presented as n (%). The p-values are calculated using a Sign test.						

4.2 Study II – Clinical judgment

4.2.1 Clinical diagnosis

Twenty-five of the children were clinically comprehensively diagnosed with ASD, five children had autistic traits, and four children had no ASD/no autistic traits.

4.2.2 Assessment settings: Clinical judgment – final diagnosis

In Table 3 the main results are presented. The sensitivity versus final clinical diagnose was highest for DISCO (0.74), lowest for DQ (0.40), and for all

other assessments it ranged between 0.60 to 0.68. The specificity was higher, over 0.89 for all raters, except for language assessment. Corresponding 95% confidence intervals were rather wide due to the small number of subjects. The poorest agreement (47%) with comprehensive clinical diagnosis was obtained in the DQ assessment setting, for which weighted kappa was only 0.28, and which indicated systematically less ASD than the clinical diagnosis ($p=0.007$). All other assessments showed agreement between 58% and 68% and weighted kappas between 0.33 and 0.43.

The DQ assessors “underestimated” almost half (44%) of the children in terms of diagnostic “level” in relation to clinical diagnosis (final clinical diagnosis showed more ASD), whereas the parent interviewers (DISCO) “underestimated” a much smaller proportion (22%) in this respect. In contrast, the DQ assessors “overestimated” only 9% and the parent interviewers 19%.

Table 3. Sensitivity, specificity, and agreement across measurements between individual assessments and comprehensive clinical diagnosis

Assessment	Sensitivity ASD Clinical diagnosis (95%CI)	Specificity ASD Clinical diagnosis (95%CI)	Weighted kappa (95% CI)	n (%) Agreement	Clinical diagnosis more ASD	Clinical diagnosis Less ASD	P-value Systematic changes between Raters and Clinical diagnosis
Medical/neurologic- psychiatric	0.64 (0.43; 0.82)	0.89 (0.52; 1.00)	0.40 (0.17-0.64)	21 (62%)	9 (26%)	4 (12%)	0.2668
DQ	0.40 (0.21; 0.61)	1.00 (0.66; 1.00)	0.28 (0.09-0.47)	16 (47%)	15 (44%)	3 (9%)	0.0075
Language	0.63 (0.41; 0.81)	0.78 (0.40; 0.97)	0.33 (0.08-0.59)	19 (58%)	9 (27%)	5 (15%)	0.4240
DISCO (parent interview)	0.74 (0.52; 0.90)	0.89 (0.52; 1.00)	0.40 (0.20-0.59)	20 (63 %)	7 (22%)	5 (16%)	0.7744
ADOS	0.60 (0.39; 0.79)	1.00 (0.66; 1.00)	0.43 (0.21-0.64)	21 (62%)	10 (29%)	3 (9%)	0.0923
Preschool/home	0.68 (0.46; 0.85)	0.89 (0.52; 1.00)	0.44 (0.18-0.69)	23 (68%)	8 (24%)	3 (9%)	0.2266

Note: The sensitivity and specificity are calculated on the dichotomous variables ASD/No ASD, where “No ASD” also contains the classification “probably/possible ASD”. Weighted kappa, % Agreement, Clinical diagnosis more ASD, Clinical diagnosis less ASD and P-value are all calculated at the 3-point division; ASD, ASD probable/possible and No ASD.

4.2.3 Individual clinical judgment – final diagnosis

A considerable degree of variability was found as regards agreement between individual assessor diagnostic codes and final diagnosis, both between and within different professional categories (Table 4).

Table 4. Individual assessor's agreement with final diagnosis

Assessor	Same code as final diagnosis/ Number of assessments
Medical/neurologic-psychiatric	
1	14/20 (70%)
2	2/2 (100%)
3	1/3 (33%)
4	4/9 (44%)
DQ	
1	2/3 (67%)
2	3/9 (33%)
3	2/9 (22%)
4	13/9 (69%)
Language	
1	19/31 (61%)
2	0/2 (0%)
DISCO	
1	14/17 (82%)
2	2/6 (33%)
3	4/9 (44%)
ADOS	
1	8/15 (53%)
2	13/19 (69%)
Preschool/home	
1	11/19 (58%)
2	12/15 (80%)

Note: One child did not have language evaluation and two did not have the DISCO.

4.2.4 Gender aspects

The DQ assessors failed to agree with the final clinical diagnosis in all six girls participating in the study. The ADOS assessors agreed in 1/6 (17%), the SLP in 2/5 (40%), the child psychiatrist/neurologist in 3/6 (50%), the education specialist in 4/6 (67%), and the parent interviewer (DISCO) in 3/4 (75%). All the girls were clinically comprehensively diagnosed with ASD.

4.3 Study III – Gender

4.3.1 Clinical diagnosis

Twenty of the 40 children were diagnosed with autistic disorder, eighteen with atypical autism/PDD-NOS (of whom three were considered borderline with marked autistic traits), and two with Asperger syndrome. Nine of the girls had autistic disorder, and 9 had PDD-NOS. One girl had Asperger

syndrome and 1 had marked autistic traits. For boys, the corresponding figures were 11 boys with autistic disorder, six with atypical autism, and one boy with Asperger syndrome. In addition two boys had marked autistic traits.

4.3.2 ADOS measures

Thirteen children (7/20 girls; 6/20 boys) did not meet ASD algorithm criteria according to ADOS and 14/40 (7/20 girls; 7/20 boys) according to ADOS-R. Severity scores according to the ADOS-R, ranged from 1 (=low severity level) -10 (=high severity level), with a mean of 4.7, SD= 2.5 for all children (Table 6).

4.3.3 Development measures

The mean total Griffiths' DQ score was 84, SD=21.5 (33-121). Six of the girls and six of the boys had DQ-scores at 70 or below. Mean DQ for language according to Griffiths' testing was 68, SD= 21 for all children (for girls; 70, SD= 24.4, for boys; 65, SD= 17.6, n.s.), whereas gross motor, personal – social, eye- hand coordination, performance, and practical reasoning skills ranged from 81 – 94 with no significant differences between boys and girls (Table 5).

According to the VABS parent interview for the whole group, the mean for social skills (76, SD=9.8) (girls; 78, SD=8.2, boys; 73, SD= 10.7, n.s.) and communication (77, SD= 13.9) (girls; 81, SD=16.4, boys; 74, SD=10.7, n.s.) were lower than daily living skills (84, SD=12.7) (girls; 88, SD=13.2, boys; 81, SD=11.3, n.s.) and motor skills (85, SD= 13.4) (girls; 87, SD=15.9, boys; 83, SD=10.9, n.s.).

Table 5. ADOS severity score, Griffiths Developmental Scales (GDS) and VABS in girls and boys with ASD

Measures	Girls (N=20)				Boys (N=20)				P-value
	N	M	SD	Range	N	M	SD	Range	
ADOS Severity score	20	4.50	2.50	1-10	20	4.85	2.60	1-10	0.8163
GDS									
Gross motor	16	84.4	22.5	36-117	18	85.2	21.2	45-130	0.9038
Personal Social	18	88.8	28.0	40-163	18	81.5	21.7	43-119	0.5789
Language	17	70.4	24.4	24-106	18	65.4	17.6	36-107	0.6678
Eye and hand	18	83.5	20.6	36-116	18	77.7	19.5	31-105	0.3418
Performance	18	85.1	25.1	31-123	18	83.5	18.0	28-110	0.9244
Practical Reasoning	8	89.3	30.4	24-116	4	102.3	14.5	81-112	0.3502
Total *	20	85.5	22.8	33-121	20	82.3	20.7	37-120	0.5607
VABS									
Communication	18	80.7	16.4	38-100	20	73.9	10.7	55-89	0.1039
Daily Living Skills	18	88.3	13.2	66-114	20	80.6	11.3	62-97	0.0813
Socialisation	18	78.3	8.2	65-90	20	73.4	10.7	52- 92	0.1240
Motor	18	86.8	15.9	61-120	20	83.4	10.9	67-107	0.4730
Total	18	82.6	12.0	66-102	20	75.0	8.9	59-90	0.0743

*) Four of the children were tested by WPPSI

4.3.4 Language measures

For a majority of the children, expressive language was problematic. Nineteen of the 40 (8/20 girls, 11/20 boys) lacked speech altogether or used only a few single words or communicative sentences. Nine children (6/20 girls, 3/20 boys) talked a great deal but with echolalia and 12 children (6/20 girls, 6/20 boys) had functional communication. Receptive language measured with RDLS was also problematic for a majority of the children with a mean score of 16 points for the whole group, corresponding to ≤ -1 SD for 24-month-olds when their mean age was 37 months. There was also a marked variation in receptive language ability on the RDLS (range 0-52 points).

4.3.5 Global functioning

The vast majority of the children (37/40) were estimated as having mild, moderate or severe clinical impairment and CGAS scores ranged from 10–75 (girls; 10-59, boys; 10-75) (mean=44, SD=11.8). The child with the highest CGAS score (75) had autistic traits and considered borderline for atypical autism.

In conclusion there was no significant difference between the girls and the boys on any variable tested, i.e. regarding clinical diagnosis, cognitive level (Griffiths'), reciprocity and RRB (ADOS), adaptive behaviour (VABS), comprehension (RDLS), expressive language level, ADOS-R severity score, or overall global functioning (CGAS).

4.3.6 Correlations between different test instruments

There were strong correlations between a) ADOS and ADOS-R ($p < .0001$ girls and boys); b) ADOS severity score and CGAS ($p = .0046$ girls, $p = .0050$ boys); c) Griffiths' hearing-speech and VABS communication ($p = .0004$ girls, $p = .0017$ boys); d) Griffiths' total and VABS total ($p = .0002$ girls, $p < .0001$ boys), and e) Expressive language level and RDLS ($p = .0063$ girls, $p = .0005$ boys).

4.4 Study IV – Parents and teachers

4.4.1 Responders and non- responders

Baseline characteristics for children whose parents responded compared to those whose parents did not respond did not differ significantly in any respect (age, diagnosis, severity, or family situation) (Table 6).

Table 6. Baseline child and family characteristics by responder status

Variable	Responders (n=34)	Non-responders (n=12)	P-value
Boys	26 (76%)	8 (66%)	
Girls	8 (23%)	4 (33%)	0.76
Age (months)	37 (6.2) 38.0 (23.0; 47.0)	35 (5.0) 36.0 (26.0; 41.0)	0.29
Autism	15 (44%)	6 (50%)	0.98
Atypical autism	11 (32%)	3 (25%)	0.93
Autistic traits	4 (12%)	1 (8%)	1.00
ADHD	2 (6%)	0 (0%)	1.00
Language disorder	5 (15%)	4 (33%)	0.33
Developmental delay	11 (32%)	2 (17%)	0.52
Epilepsy	1 (3%)	0 (0%)	1.00
Severity score	4.74 (2.72) 5.00 (1.00; 10.00)	5.17 (2.92) 5.50 (1.00; 9.00)	0.63
CGAS	42.6 (10.4) 43.0 (10.0; 62.0)	44.3 (12.4) 40.0 (31.0; 73.0)	0.58
Swedish parents	25 (73%)	0 (0%)	
Immigrant parent(s)	9 (26%)	12 (100%)	<.0001
Single parent	5 (15%)	1 (9%)	
Two parents	29 (85%)	10 (91%)	1.00
Siblings	29 (85%)	8 (67%)	0.33
For categorical variables n (%) is presented.			
For continuous variables Mean (SD) /Median (Min; Max) / n= is presented.			
For comparison between groups Fisher's Exact test was used for dichotomous variables and the Mann-Whitney U-test was used for continuous variables.			

4.4.2 Parent questionnaire time 1

The results from the questionnaires are presented as subdivided according to responses, different themes, and specific questions (Q) on the parent questionnaires (Appendix 3).

First concerns (Q 1-2): The first concern about the child's development had been expressed by a clear majority of the parents themselves. Half of the responding parents had their first concerns when the child was between 1-2

years of age (a few started to worry even earlier) and about 1/3 started to worry between child age 2-3 years.

Before the process started (Q 3-6): Half of the parents said that the waiting time for assessment was reasonable, and the other half stated that they would have wanted the process to start even earlier. Before the diagnostic process started, the majority stated that they definitely got sufficient information at the CNC.

The diagnostic process and information (Q 7-11): The amount of components included in the diagnostic assessment was found to be adequate by the majority of the 34 parents. More than half of the parents were satisfied regarding the length of the assessment time. The vast majority of the parents found the information that was given at the information sharing conferences to be adequately detailed.

Overall rating (Q 12): A clear majority responded that they believed that the child had been diagnostically assessed at the right time, and none of the parents regretted that the diagnostic assessment had been conducted.

4.4.3 Parent questionnaire time 2

Parent questionnaire from time 2 (Q 13-15): Slightly more than half of the 24 parents who responded to the second questionnaire after about one year, reported that they felt that increased teacher knowledge after the diagnosis had definitely benefited their child. Almost half of the parents stated that they felt more secure in their role as a parent after the assessment, and only a few felt more stressed.

4.4.4 Parent questionnaires compared

No significant systematic changes between the questionnaires from time points 1 and 2 were found.

4.4.5 Teacher questionnaire

The results from the questionnaires are presented as subdivided according to responses, different themes, and specific question (Q) on the teacher questionnaires (Appendix 4).

First concerns (Q 2-5): Slightly more than half of the teachers had had their first concerns when the child was 1-2 years old and a third between child age 2-3 years. The duration from the first concern to the start of the diagnostic process was considered reasonable by the majority.

The diagnostic process and information (Q 1, 6-8): The majority of the preschool teachers were satisfied with their opportunity to share their experiences about the child. They were also mostly satisfied with the information about the results. The clinical results corresponded with the teacher's impression of the child in most of the cases.

Preschool teachers' reflection (Q 9-12): A majority of the teachers reported that their understanding of the child's needs had been positively affected by the diagnostic information. A clear majority were satisfied that the diagnostic evaluation was made at this time of the child's life. Most of the teachers considered themselves to have been actively involved in the assessment.

4.4.6 Further analyses of the questionnaires

Parents of girls rather than boys tended to have preferred more time at the parent conference. On the parent questionnaire time 2 the parents of boys were more satisfied with the given information before the diagnostic process started than were the parents of girls.

Preschool teachers reported that their knowledge about the needs of the girls had improved more compared to the boys after the diagnostic process ($p=.047$), and that they had more certainty in respect of how to approach girls than boys ($p=.047$).

No significant differences were found on the four identical questions from the parent questionnaire (Q 2, 3, 11) and teacher questionnaire (Q 4, 5, 6, 11).

In the three cases where someone other than the parent expressed the first worries about the child, the child's problems were significantly milder measured by the ADOS severity scale than those of the other 31 children ($p=.043$). Both the parents ($p=.005$), and preschool teachers ($p=.017$) had their first concerns about the child's development earlier in cases with higher severity level.

5 DISCUSSION

5.1 General findings

The Preschool study demonstrated that observations of young children with suspected ASD, yielded almost the same results in preschool and in the clinic, when observations were targeting the same areas. We cannot determine whether or not one of the methods is more useful than the other. However, when also taking the results of the Clinical judgment study into account, the conclusion is that observation in everyday settings (in preschool or at home with parents) provides very important information in ASD assessments of young children. The Clinical judgment study also confirmed that comprehensive clinical diagnosis should still be regarded as the gold standard, and that multidisciplinary assessment of ASD and other ESSENCE problems is important.

No significant differences were found in the Gender study when comparing the diagnosis or developmental profiles in girls and boys worked up for ASD after general population screening.

The Parent and teacher study demonstrated that both parents and teachers had had very early concerns of their children with suspected ASD, even when, as was the case in all preschoolers in the present study, ASD had been suspected after general population screening. Parents and teachers were also appreciative of the assessment process in general, and none of them regretted that the child had been assessed.

5.2 General discussion of limitations and strengths

A larger study group would have been preferred in all of the four studies, but the constraints of the AUDIE project did not allow inclusion of more cases. In addition, specific designs of the sub-studies imposed constraints, for example several “extra” assessors to avoid bias in the Clinical judgment study, meaning that the number of participants had to be even more limited and collected under a limited time period.

Nevertheless, the participants were consecutively selected. Study I was performed and based on data from the first part of the AUDIE project, and

study IV was performed on data obtained during the later part of the project (when Ethics approval for the questionnaire study had been obtained).

There were no non-ASD comparison groups in any of the four studies, nor were there any controls for type or style of assessment method/procedure. However, in study I, the aim was to compare two settings for an observation aiming to detect ASD symptoms and signs, and it was not intended to be a comparison of children's problems. In study II we do not know how the results might have turned out if we had had a more mixed sample (not only children with suspected ASD problems) to compare with. Because of the lack of comparison group, we were also unable to study possible differences between our diagnostic process and other models, regarding the parent and teacher experiences in study IV.

Within the context of study II, no specific interrater reliability study across clinicians within the same professional category was possible to perform, for example between the different education specialists. However, for the education specialists we already had some interrater reliability results from preschool observation in study I, where agreement was good to very good.

The sample size in study III limited the potential for further subdivision into more homogeneous groups such as according to ethnicity, parental education level etc. One could argue with our inclusion of some children assessed with WPPSI-III in the process of DQ-matching, when most children in the study had been evaluated with the Griffiths. However, all children assessed with WPPSI-III showed an intelligence quotient (IQ) level around 100, indicating an average IQ. Also, we consistently matched girls with boys only on the basis of results obtained using the same instrument.

Despite the mentioned limitations, a major strength is that the overall study sample was recruited from the general population in Gothenburg. After the ASD screening was introduced, the rate of children < 4 years of age referred for ASD assessment in Gothenburg increased from n=2 in 2005 (when screening had not been introduced), through n=24 in year 2008 to n=78 children in 2011. This, and the general population prevalence in our preschool sample of 0.8% ASD (which is not far from current estimates of lifetime prevalence of ASD), argues in favour of the study groups included here being very representative.

5.3 Discussion of results obtained in each of the four studies

5.3.1 The Preschool study

The main finding of this study was that preschool observation by an autism-experienced rater, yielded almost the same amount and type of information as highly structured ADOS assessment in a specialised clinic setting. The only domain where a significant difference between the two settings was found was “initiation of joint attention”, which is suggested to be one of the key difficulties in young children with ASD (Charman et al., 2000; Dawson et al., 2004). The ADOS at the clinic indicated more problems in that area than did preschool observation. Based on the results of the present study we cannot determine which of the two observation settings is more informative about the child’s “true” level of joint attention. However, one could speculate that the preschool setting is familiar to the child and the clinical setting is new, and that the child might therefore show more “impairment” in the new environment.

The majority of Swedish children attend preschool, and the teachers there have a lot of knowledge that potentially could provide information about how the child copes with different situations. Some of this information might be very important in the diagnostic process, not least when considering the results obtained in study II, where clinical judgment in connection with preschool observation was suggested to be very important for the final diagnosis.

The findings in the Preschool study (if confirmed by other researchers) suggest that observation in preschool, using a structured protocol such as the one included here, could be seen as a very adequate basis for rating autism symptoms. This would have important implications for ASD clinical assessments, but also for research. However, recommendations in respect of what kind of instrument that should be used (e.g. ADOS in the clinic or preschool observation) would have to be made on an individual basis. Flexibility and individualisation in clinical practice are important; every child is a unique individual. Clinical experience suggests that there are cases where both types of observation are needed, where the symptoms of ASD are less clear and have to be further evaluated in several different settings.

Finally, extending the implications of the study, preschool teachers should receive education about ASD and be encouraged to make observations and documentations of the child’s functioning in his/her everyday environment.

Early interventions have been suggested to be important (Dawson et al., 2010; Eikeseth, 2009; Myers & Johnson, 2007; Rogers & Vismara, 2008), and there are indications in the literature e.g. (Klintwall, Gillberg, Bolte, & Fernell, 2012) that attitudes and interventions in the preschool, initiated by the teachers themselves at an early stage, may be particularly beneficial. One could question whether it is ethical to make assessments of young children when you do not have “a lot” to offer, but clinical experience (my own included) has shown that awareness of the needs of the child is – in itself - of great importance in terms of educational interventions in preschool, even if - possibly, but not necessarily – more could have been achieved with more recourses.

5.3.2 The Clinical judgment study

On the basis of the results obtained in study II, it seems reasonable to conclude that multidisciplinary assessment by several team members is important, not least because of the variability of “first impression diagnosis”. Clinical judgment is considered the gold standard basis for clinical diagnosis of ASD. This is in line with results obtained in earlier studies (Charman & Baird, 2002; Klin et al., 2000; Steiner et al., 2012).

This Clinical judgment study found only poor to moderate agreement between some of the “blind” clinical assessors’ individual preliminary diagnosis and the final comprehensive conjoint clinical diagnosis. Also, agreement across types/classes of raters was not perfect. However, a tendency for “best fit” with final conjoint clinical diagnosis was found in clinical judgment made after preschool/home free-field observation of the child, and the poorest was for that made in connection with structured DQ assessment. This is, perhaps, not very surprising; the everyday environment is usually not as structured as an assessment setting in a clinic. In preschool there are same-aged peers, usually many toys, and many other impressions that the child has to deal with. In addition, when comparing with peers, ASD symptoms often stand out in a more conspicuous fashion to the observer. The DQ evaluation is considered important in neuropsychiatric assessments, where the aim is to evaluate the child’s developmental level. This means that adjustments have to be made in the test situations, meaning fewer items of distraction, fewer people in the room etc, which may mask the ASD symptoms to some extent.

The preschool/home observation might be seen as the most informative assessment setting in this study, but the parent interview also corresponded

well with the final diagnosis. These findings are also in line with previous research (Huerta & Lord, 2012).

Even if the number of girls was limited in the study (n=6) and the results therefore should be interpreted with considerable caution, it is interesting to note that none of the girls problems were “overestimated” (in terms of clinical judgment), whereas many of the boys problems were, particularly as there were no significant differences as regards developmental profiles or diagnosis in the gender study. In addition, the clinical judgment in the six girls immediately after DQ-assessment did not agree with final diagnosis in a single case. Given that all the assessors contributing to the study had many years of experience of ASD assessment in young children, this finding, in itself, is an argument for further research as regards possible gender differences.

It is important to underline that the individual clinical judgments were made and documented at the first meeting with the child. For some tests used in this study, the examiner would have more than one test session, where additional information might have changed the impression. Also, some assessors might, more generally, make more cautious assessments at the first meeting with the child. One can only speculate how a different research approach could have been used and how this might have affected these results. One such approach could have been to let 2-3 examiners from the same profession observe the assessment performed by a colleague through a one-way screen or video. This would have reduced the risk of bias due to different children’s variation as regards symptoms over time and across settings, even though it would have detracted from the positive aspects of seeing the child in different settings, and particularly in situations which are more “true to life”.

5.3.3 The Gender study

No significant differences were found in this study sample between young preschool girls and boys with regard to developmental profiles. This is, to some extent, in contrast with previous studies where differences have been observed in “non-severely-retarded” girls and boys with ASD (Dworzynski et al., 2012; Giarelli et al., 2010; Kopp & Gillberg, 1992; McLennan et al., 1993). However, our participants, unlike in other studies, were recruited from the general population and there was an equal number of girls and boys. It is of interest that the time period for collection of the 20 girls ranged over 2 years, which has to be considered as a long time compared to the collection of the boys during the same time period. The girls were further matched with

boys on chronological and mental age. Because of the small sample size, no sub-grouping was possible, which mean that the results, here too, must be interpreted with caution.

There results could be interpreted in different ways;

1) In age- and DQ-matched samples of young girls and boys with ASD, there are no detectable differences. This would be in contrast to other studies (Carter et al., 2007; Hartley & Sikora, 2009; Sipes et al., 2011), in which greater communication impairment and less RRB have been suggested in girls at this age. In the present study, there were even a few weak trends as regards some of the VABS scores, where the girls appeared to have better communication and daily living skills, than the boys. This would then be in line with other research showing that in typically developing children, girls are more socially skilled than boys (Barbu et al., 2011).

2) When children are screened at early ages, both girls and boys with ASD (at least those with major language problems) are identified early on.

3) There is still a group of girls, yet to be identified, who were missed in the screening process. This could be the group of girls previously described with higher IQ, better language and, at least superficially, better social skills (Giarelli et al., 2010; Kopp & Gillberg, 1992; McLennan et al., 1993). Given that the main portion of this study sample was referred after screening and included in the Gothenburg population study (Nygren, Cederlund, et al., 2012), this would seem to be the most likely explanation.

Finally, results obtained on the different instruments used here showed strong correlations with each other. Does this suggest that we are using too many instruments in the diagnostic process in ASD? It does appear that often, we do not need them all. However, we need to have different instruments *available*, which does not mean that we have to use them all in all cases. It is important to underline that the results discussed in this context pertain to formal “tests” results, not to be confused with results obtained at first clinical judgment, as in study II.

5.3.4 The Parent and teacher study

The results from this study indicate that parents of preschool children with ASD, have concerns about the child early on. In line with previous research (Chamak et al., 2011; Ozonoff et al., 2009; Ryan & Salisbury, 2012; Siklos & Kerns, 2007), the majority of parents begin to worry before the child has turned two years. In only three of the cases in the present study sample, did

someone other than the parents express the first worries about the child, and according to the ADOS severity scale, these children had milder problems and probably would have been less obviously “atypical”.

The majority of the preschool teachers, had concerns about the child’s development at child age 1-2 years, which probably means that they noticed problems as soon as the child began preschool. Clinical experience from preschool shows that some parents share their worries about the child with the teachers at a very early stage when the child begins preschool, but there are also parents who do not. Some parents hope that the problems will disappear when the child begins preschool and receives professional educational stimulation, or when the child gets older. It can be a challenge for both parents and teachers to find an appropriate forum to start talking about the child’s problems.

None of the parents in this study regretted the assessment, even if there were four (out of 34) parents who had preferred the assessment to be performed a little later in the child’s life. Two of these parents had children with milder problems (aged 3-4 years) and two were very young (23 and 27 months respectively). Obviously, the vast majority of parents are both worried about the child and anxious for the child to be assessed at very early age, (Mansell & Morris, 2004; Reed & Osborne, 2012).

The clinical diagnostic process in these studies included relatively many assessment parts (10-12 visits to the clinic), which could have been found to be burdensome for the parents. However, there were some parents who had wanted even more assessments, but overall, parents were satisfied with the process, and with the information after the assessment. Given that the parents were present in most of the assessment parts (not at preschool), one could speculate that their own insight into the child’s problems/strengths in different areas increased during the process. The majority of the preschool teachers felt involved in the diagnostic process and the majority of the parents found the information collected from preschool to be important. Speed of diagnosis has been reported as important for parents (Chamak et al., 2011; Osborne & Reed, 2008; Reed & Osborne, 2012) and half of the parents in this study reported that they would have preferred the assessments to start even earlier. Despite this, most parents were satisfied with the time period of the diagnostic process.

Only about half of the parents and the teachers had become “calmer” respectively more confident in approaching the child after the diagnosis. This

suggests that we have to improve the support to parents and give teachers more guidance in their educational work.

Even if this study involved a very small number of girls, it is of interest that the final diagnosis was reported to help the teachers to better understand the needs of the girls, but not so much in the case of the boys. It is possible that the boys' needs had already been more obvious for the teachers. Another explanation could be that teachers have different interpretations of ASD-associated problems when it comes to girls as compared with boys. An example might be that girls, on the surface, appear to be more socially skilled, but when more of reciprocity is required, problems arise. In contrast to girls, boys' interaction problems may be more obvious.

5.4 Conclusion

Preschool observation yields very important information about children with suspected ASD and should be included in the diagnostic process.

Multidisciplinary assessments are crucial, and comprehensive clinical diagnosis should be regarded as the gold standard in ASD.

Girls and boys identified in the early years with ASD problems appear to be very similar. Even if these results (due to the limited sample size) have to be interpreted with caution, one has to consider that these children were consecutively recruited from the general population during a time-period of 2 years, suggesting that there may be young girls not yet identified in the screening procedure.

Parents and preschool teachers have very early concerns about children with suspected ASD and early diagnosis and a relatively quick diagnostic assessment process are considered important both by parents and teachers.

5.5 Implications for clinical practice

5.5.1 Overall clinical practice

ASD training: It is generally agreed that early intervention is important in ASD, particularly in cases that present with impairment at a very early age. ASD is not rare. It follows that there is a need for psychometrically sound (and "cost-effective") assessment tools and well-developed routines for the process of diagnosis, from early concerns through assessment and on to intervention. Young preschool children cannot speak for themselves in terms

of what their problems are, but are dependent on adults who can observe and evaluate the child's problems and needs. For this reason, the number one priority should be to disseminate knowledge about typical and atypical child development, both in child care, child health care centres, at preschools, and in society more generally. Clinicians meeting young children have to be well educated in ASD (and other ESSENCE) in young children, and to be able to detect symptoms that differ from the typical development in preschoolers. This was the first step in the Gothenburg screening programme (Nygren, Sandberg, et al., 2012).

Routines and instruments for early detection: No differences between girls and boys in this study sample were found, and although no major conclusions could be made out of this, it could mean that if children are screened at early ages, even the girls who are detected must receive early interventions. On the other hand, we also have to consider that the present screening instruments may not be sensitive enough to detect all children, girls in particular, where the symptoms may not be obvious or "typical enough" for recognising ASD or other ESSENCE problems. For these reasons, continued development of routines as regards early detection, assessment and, interventions is needed in health care, child development clinics, and habilitation centres. The results of this thesis further show that both parents and teachers usually have very early concerns about the child, and that early assessments are experienced as positive, both by parents and preschool teachers.

Parents' participation in the diagnostic process: Previous research suggests that it is important for parents to feel involved and to be informed during the diagnostic process (Abbott et al., 2013; Reed & Osborne, 2012). This includes preparation before the process starts. Information from parents (parental interviews) as regards ASD symptoms has also been shown to be important (Huerta & Lord, 2012), which was confirmed in this study. This leads on to the need to discuss the importance of a shared common language, not only between professionals, but also between parents and professionals to be able to understand each other. It also requires routines for keeping parents informed during the process, and especially when the diagnosis is completed and is presented to/discussed with the parents.

From assessment to intervention: Reviews of routines for handing over from assessment to intervention have to be done, to reduce waiting-time and to promote the right intervention to be initiated at an early stage. More and improved collaboration between preschool teachers, parents and, clinicians is all important. In Sweden, children with ASD and/or development delay are

referred to the habilitation services, and children diagnosed with language disorders without ASD are usually referred to the unit of speech and language pathology (SLP). However, children with ADHD or other ESSENCE problems without ASD or language disorders are often referred to child health care and/or preschool, and generally receive less specialised support than those referred to habilitation services or SLP. In other words, there are children and families who get limited support in relation to their actual needs. In the future, efforts should be based on the child's needs and functional state, as described in the Interventional Classification of Functioning, Disability and Health (ICF) (Björck-Åkesson et al., 2010; WHO, 2001) rather than just on diagnosis. A transparent organisation, involving both diagnostic assessments and interventions for children with ESSENCE problems and in need of special support, would - in all probability - benefit both the child and the surrounding network.

5.5.2 Diagnostic tools and professions

Observations in everyday situations: Based on the results obtained in this thesis, it is clear that observation in preschool provides very important information about the child and his/her abilities in the everyday environment. This should therefore be considered as one of the key elements in the diagnostic assessment of preschool children. In the preschool setting there are typically developing children, and the observer will have a better opportunity to decide whether or not the child with suspected ASD is clearly different from his/her age-peers in terms of social communication and/or behaviour. In the preschool setting the child is expected to adapt to the preschool routines, interact with other children, and deal with a lot of unpredictable sensory stimulation, situations that are usually problematic for these children. For this, it is not surprising that preschool observations can provide important information about the child's problems.

Multidisciplinary teams: What different professions should be involved in the neuropsychiatric assessment of young children? Results of this study, suggest that multidisciplinary teams are important, perhaps especially as regards children with the less typical neuropsychiatric symptoms, where more extensive information is needed to arrive at valid diagnosis. In Sweden, education specialists are not included in all neuropsychiatric assessment teams, but based on our study, (and clinical experience) they are very important. Development of multidisciplinary assessment teams should be prioritised in clinical practice.

One could question if there has to be an education specialist making the observations in preschool and making the interviews with the preschool staff. However, it is important to consider the importance of collegial collaboration and “shared language” aspects. The education specialist in his/her basic skills has experience of working in preschool (and/or school) and based on this will be able to ask the right questions regarding functioning in preschool/school. Clinical experience shows that during the interview with the preschool teachers, thoughts on interventions begin to take shape, and even without having the final diagnosis; teachers can begin to make adaptations that will benefit the child.

5.6 Implications for research

Diagnostic process: Replications are needed on larger samples of very young children with suspected ASD examining the usefulness of free-field preschool observation in the diagnostic process relevant for ASD (and other ESSENCE). Types of instrument and number/types of clinicians needed to provide the most valid comprehensive diagnosis should be in focus. There is an additional need to examine whether or not observation tools/interviews/questionnaires would benefit from including more gender-specific items. Aspects of the patient’s own participation in the ASD diagnostic process (where for young preschool children the parents could be considered as a representative for the child), will also be an important focus for further research (Swedish Council on Health Technology Assessment, 2012).

Gender: More research focused on girls is important, but we also need to identify what is regarded as male and female traits and to understand masculinity and femininity in a broader gender perspective. We need to remember that there not only are differences between girls and boys, but also between girls and between boys. Girls with ASD, especially those with a higher IQ level, are missed or identified later in life than boys. However, there may also be boys who are not being detected, when they do not fit the current “norm” for male ASD traits. In the future, we may not be discussing differences in males or females, but different ASD profiles in both genders. It will also be important to consider how parenting affects child development and how this in turn might affect symptoms in ASD. Parenting differs between cultures and families as well as expectations of boys and girls. This should be taken into account in ASD research, and further in the assessment process.

Early signs: Prospective - retrospective studies making use of family-produced video-clips of newborns and babies later diagnosed/not diagnosed with ASD will be important for further refinement of the earliest “phenotype” of ASD (and other ESSENCE). Today, most parents have access to cameras and smart-phones with which they document the child’s early years. This provides information about possible symptoms that parents or teachers did not observe when the child was younger, but may be possible to pick up on in blindly examined “case-control” photos or movies retrospectively. (Such studies are actually prospective in nature since the material examined was collected before the diagnosis and with no knowledge of the outcome).

Family: Further research involving the family around the child, not only the parents, but also siblings and the larger social network, would provide the basis for a better understanding of the family and the network needs, during the time of detection of the problems, the diagnostic process and in connection with interventions. Follow up studies are important as regards children being detected through screening and assessed in early years, both in terms of the child’s development, and of how the early diagnosis has affected the family and their quality of life. There is also a need for studies in this field focusing on similarities and differences across ethnicity and culture.

DSM-5: In the DSM-5, there is a change from having several ASD subcategories to having them all included under one umbrella. This thesis is based on the diagnostic criteria of DSM-IV, and similar studies need to be performed, based on the criteria of the DSM-5.

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APPENDIX

Appendix 1

Pre-school observation Module 1

From the algorithm in ADOS

Name: _____

Year of birth: _____

Date: _____

Examiner: _____

Communication Points

Frequency of vocalization directed to others _____

Stereotyped/idiosyncratic use of words or phrases _____

Use of others body to communicate _____

Pointing _____

Gestures _____

Communication total _____

Reciprocal social interaction Points

Unusual eye contact _____

Facial expressions directed to others _____

Shared enjoyment in interaction _____

Showing _____

Spontaneous initiation of joint attention _____

Response to joint attention _____

Quality of social overtures _____

Social interaction total _____

Communication + social interaction total _____

Play and imagination Points

Functional play with objects _____

Imagination/creativity _____

Play/imagination total _____

Stereotyped behaviours and restricted interests Points

Unusual sensory interest in play material/person _____

Hand and finger and other complex mannerism _____

Unusual repetitive interests or stereotyped behaviours _____

Stereotyped behaviours and restricted interests total _____

The items should be scored using the same metric and criteria as the ADOS.

Appendix 2

Pre-school observation Module 2

From the algorithm in ADOS

Name: _____

Year of birth: _____

Date: _____

Examiner: _____

Communication

Points

Amount of social overtures/maintenance of attention _____

Stereotyped/idiosyncratic use of words or phrases _____

Conversation _____

Pointing _____

Gestures _____

Communication total _____

Reciprocal social interaction

Points

Unusual eye contact _____

Facial expressions directed to others _____

Spontaneous initiation of joint attention _____

Quality of social overtures _____

Quality of social response _____

Amount of reciprocal social communication _____

Overall quality of rapport _____

Social interaction total _____

Communication + social interaction total _____

Play and imagination

Points

Imagination/creativity _____

Play/imagination total _____

Stereotyped behaviours and restricted interests

Points

Unusual sensory interest in play material/person _____

Hand and finger and other complex mannerism _____

Unusual repetitive interests or stereotyped behaviours _____

Stereotyped behaviours and restricted interests total _____

The items should be scored using the same metric and criteria as the ADOS.

Appendix 3

Parent questionnaire. (Question 13-15 were added at time 2 and were not included at time 1)

Questionnaire for parents, one year after diagnostic evaluation:

Your child has been diagnostic evaluated at the CNC under the project "Autism Detection and Intervention in Early life" and we hope that you would like to help us to improve our work by answering the following questions:

1. Who expressed the first concerns about your child's development? (Examples; myself, preschool, family, friends, health care system etc)

Describe:.....
.....

2. – When did your first concerns about your child begin?

1. Before 1 year of age
2. Between 1-2 years
3. Between 2-3 years
4. After the 3rd birthday
5. I have not been worried myself

3. – Would you have preferred a longer period of time between raising your first concerns and the start of the diagnostic process?

1. Yes, it started too fast
2. No, it felt just right
3. No, it could have started earlier
4. I had wished that no assessment had been conducted

4. – Did you feel that you as a parent were allowed to say no to the evaluation?

1. Yes
2. Maybe, but I felt persuaded
3. No

5. – When you and your child came to the CNC, were you aware of the question surrounding your child's development that was written in the referral?

1. Yes
2. Partially
3. No

6. – Do you think you were given enough information at the CNC with regard to the diagnostic process?

1. Yes
2. Partially
3. No

7. – What was your opinion on the diagnostic process?

1. Too many parts/components
2. Adequate amount of components
3. Should have been more extensive

8. - What do you feel about the entire evaluation process?

1. Too long
2. Adequate
3. Too short

9. – How do you feel about receiving input from preschool?

1. Positive
2. Negative
3. It probably did not contribute so much

10. –What is your opinion of the final meeting post evaluation?

1. Adequately detailed
2. Too detailed
3. Too limited
4. We needed more time

11. – After the evaluation we had a meeting with preschool staff and the habilitation centre where we gave information about the results - How did you find the information that was provided?

1. Adequately detailed
2. Too detailed
3. Too limited
4. We needed more time

12. – On reflection, do you wish that the diagnostic evaluation had been carried out when the child was older?

1. Yes
2. No
3. I wish that no evaluation had been conducted

13. If your child still is at the same preschool as at the time of the assessment, do you feel the child has benefited from the preschool teacher's knowledge?

1. Yes
- 2 Partially
3. I have not noticed any difference

14. If your child has moved to another preschool after the evaluation, what was the reason for this?

1. Because of the child's need of support
2. We, (the family) have moved
3. We have moved the child to another preschool for other reasons

15. How do you feel now after the diagnostic evaluation compared to before?

1. I have become more secure as a parent
2. I feel more stressed and worried
3. There is no difference

Appendix 4

Teacher questionnaire

Preschool experiences after the diagnostic process

It has now been a few months since you participated in a diagnostic evaluation of a child in your preschool.

1. –Do you think you got enough of an opportunity to share your knowledge about the child?

1. Yes
2. Partially
3. No

Comments.....
.....

2. Prior to the evaluation, did you have any concerns about the child's development?

1. Yes
2. Some concern
3. No

3. – If you have answered option 1 or 2 in question 2, did you tell the parents about your concerns?

1. Yes
2. We planned to do that
3. No

4. - How old was the child when you first started to worry?

1. Younger than 1 year
2. Between 1-2 years
3. Between 2-3 years
4. Older than 3 years

5. – What do you think about the time period that elapsed between when concern for the child emerged and the start of the diagnostic process

1. The time frame is reasonable
2. We are required to wait too long
3. You are too quick to evaluate

6. After the evaluation we had a meeting with the staff from preschool and the habilitation centre where we gave information about the results. - How did you find the information that was provided?

1. Adequately detailed
2. Too detailed
3. Too limited
4. We needed more time

7. – Would you have liked further contact with the CNC after the evaluation?

1. Yes and we have asked for more contact
2. Yes, but we have not asked for further contact
3. No

8. – To what extent do you feel that the result from the evaluation is consistent with your opinion of the child?

1. Very much
2. Partially
3. Not at all

9. – How do you think your understanding about the child's needs have been affected after the evaluation?

1. In a positive way
2. Partially
3. No difference

10. – How do you feel now after the evaluation compared to before?

1. We are more secure now as to how best approach the child
2. We are more uncertain now as to how to approach the child
3. No difference

11. – On reflection, do you wish that the diagnostic evaluation had been carried out when the child was older?

1. Yes
2. No
3. I wish that no evaluation had been conducted

12. – What is your overall experience of your involvement in the evaluation together with the CNC?

1. We felt involved
2. We wanted more cooperation
3. We did not feel involved

Comments

.....
.....
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