# Aspects of Communication, Language and Literacy in Autism

Child Abilities and Parent Perspectives

**Emilia Carlsson** 

Speech and Language Pathology Unit & Gillberg Neuropsychiatry Centre Institute of Neuroscience and Physiology Sahlgrenska Academy University of Gothenburg

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emilia.carlsson@gu.se

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### **Abstract**

The main aim of this thesis was to investigate literacy, 'theory of mind' (ToM) and narrative ability in children who had screened positive for autism spectrum disorders (ASD) (comprehensively assessed for neuropsychiatric problems), and relate the findings to their structural linguistic capacity, as measured by language tests at the word and sentence levels. Considering the important roles of families in shaping children's language socialisation, another aim was to explore the parental experiences of having a child go through the neuropsychiatric and language diagnostic process. The thesis includes four substudies. Almost 200 children participated in one or several of the substudies. Children with ASD were recruited after general population screening and non-ASD comparison children were recruited from schools. Eleven parents of the children with ASD were also included.

Study I, aimed to investigate early and concurrent predictors of reading ability in children who had screened positive for ASD. Children were grouped into three types of reading profiles at 8 years of age: approximately one third were skilled readers, half had difficulties with both word reading and reading comprehension and one fifth were 'hyperlexic' (i.e. strong word decoding but poor comprehension). Children who showed poor reading comprehension also displayed oral language difficulties concurrently and already at age 3 years. In Study II, a computer application, manipulated in three conditions, was used to investigate the influence of verbal support in ToM. Neither verbal support during the ToM conditions nor higher language ability in the children with ASD was obviously linked to a better outcome on the ToM task. As expected, the ASD group performed poorer than age-matched peers without ASD on the ToM task. Study III, aimed to describe oral narrative ability in children with ASD and determine how it is related to structural language ability) and non-verbal cognitive abilities in children with and without ASD. The results for the ASD group were compared with those for both an age-matched and a younger language-matched group of children without ASD. The ASD group used shorter sentences and fewer subordinate clauses in their retold narratives. Further analyses showed that nonverbal sequential reasoning and language ability explained unique variance in their narrative performance. In Study IV, in-depth interviews were conducted with parents of 11 children with ASD included in the thesis. Following a qualitative phenomenological hermeneutic method, the essence that emerged was 'negotiating knowledge' and three main themes were: 'seeking knowledge', 'trusting and challenging experts', and 'empowered but alone'.

To conclude, a clear influence of language was shown for both literacy and narrative ability in children with ASD, implicating a need for a comprehensive assessment of language abilities, in order to better clinically and educationally support children and families. However, the current study also provides evidence that structural language alone cannot explain all aspects of communicative difficulties in ASD. Future studies should continue to focus on structural language ability and other possible predictors of communication development in ASD, and also place more emphasis on the families' experiences, by involving them in developing future research.

**Keywords:** Autism spectrum disorders, communication, language, theory of mind, literacy, reading, narrative ability, children, parents

## Sammanfattning på svenska

Autism – som förekommer hos en dryg procent av befolkningen - är en tidigt debuterande funktionsnedsättning som innebär avvikelser i ömsesidig social/kommunikativ interaktion och samtidig begränsad beteenderepertoar med bl.a. repetitiva rörelser, upprepningar, specialintressen och annorlunda reaktioner på sensoriska stimuli. Kommunikativa avvikelser är ett av huvudsymtomen vid autism. Därutöver har en del barn med autism en avvikande tal- och språkutveckling. Strukturell språkförmåga (dvs. ljudsystem, ordförråd och grammatik) varierar mycket hos barn med autism – från en avsaknad av talspråk till mycket avancerad språkförmåga jämfört med jämnåriga barn utan autism

Huvudsyftet med avhandlingen var att studera läsförmåga, "theory of mind" (ToM) (förmågan att tänka sig in i andra individers perspektiv och tankar) och berättarförmåga – som är olika aspekter av kommunikativ förmåga – och relatera dessa till strukturell språkförmåga hos barn i 7-8 års-åldern. Ett sekundärt syfte var att undersöka föräldrars upplevelser av att ha ett barn som genomgått tidig screening på barnavårdscentral (BVC) och neuropsykiatrisk utredning. Avhandlingen består av fyra delarbeten.

Avhandlingen inkluderar drygt 200 barn. Barnen med autism föll ut som "screen-positiva" för autism vid 2,5 års screening på BVC. De bedömdes därefter multiprofessionellt och de har sedan följts under flera år. Barnen i jämförelsegruppen rekryterades via förskola och grundskolor. I avhandlingen var även elva föräldrar till barnen med autism inkluderade.

Delarbete I är en longitudinell studie med syftet att undersöka läsprofiler hos barn som screenades positivt för autism vid 2,5 års ålder, och hur dessa profiler hänger samman med språkliga och kognitiva färdigheter. Omkring hälften av barnen bedömdes ha svårt med både läsförståelse och ordavkodning (förmågan att läsa av enstaka ord korrekt och med flyt), en tredjedel bedömdes som goda läsare och en femtedel var duktiga på ordavkodning men hade nedsatt läsförståelse. Inget barn visade sig ha enbart svårigheter med ordavkodning dvs. svårigheter som anses kunna signalera en dyslektisk läsprofil. Det visade sig finnas en stark koppling mellan språkförmåga och läsförståelse vid åtta års ålder. Faktum är att barnen som uppvisade läsförståelseproblem vid åtta års ålder redan vid tre års ålder hade svaga resultat på språktestning.

Delarbete II är en experimentell studie med syfte att undersöka hur olika typer av verbalt stöd var associerade med förmågan till ToM, genom att använda en datorapplikation (app) på en läsplatta. Barn med autism jämfördes med jämnåriga barn utan autism och resultaten visade att barnen med autism

presterade sämre på ToM-uppgiften, oavsett vilket språkligt stöd de fick. Båda grupperna presterade sämre än förväntat med tanke på att ToM-förmågan bör vara etablerad vid 4 års ålder. Detta gör det svårt att dra några säkra slutsatser om användbarheten av "appen" och vilken betydelse det verbala stödet egentligen hade för uppgiften.

Delarbete III har syftet att studera återberättarförmågan hos barn med autism i relation till andra strukturella språkliga färdigheter (mätt med språkliga test på ord och meningsnivå) och kognitiva färdigheter (icke-verbal nivå). För att undersöka betydelsen av språklig förmåga för återberättande, jämfördes barnen med autism med barn i samma ålder samt med yngre barn med motsvarande språklig förmåga. Resultaten visade att barnen med autism presterade svagare på muntligt återberättande både jämfört med jämnåriga och jämfört med yngre barn matchade på språklig förmåga. Detta tyder på att det inte enbart är den språkliga förmågan som förklarar svårigheter med berättande hos barnen med autism. Dessutom, tydde resultaten på att berättandet hos barnen med autism kunde förklaras av förmågan att sekvensera bilder.

Delarbete IV är en kvalitativ studie som fokuserade på föräldrars upplevelser av den neuropsykiatriska utredningsprocessen. Fynden visade att föräldrarna var nöjda med information och omhändertagandet vid utredningen men att de därefter kände sig ensamma och lämnade utan hjälp. Föräldrarna beskrev att de upplevde att stöd och insatser ofta dröjde längre än förväntat.

Avslutningsvis pekar studiens resultat på att strukturell språkförmåga, mätt med test på ord och meningsnivå, har stor betydelse för läsförmåga och återberättande hos barn med autism, men att språkförmågan inte kan förklara alla svårigheter. Det behövs således både bredd och djup i den språkliga och kognitiva utredningen för att kunna stödja dessa barn och familjer på bästa sätt. Vidare behövs mer fokus på föräldrars upplevelser och att familjerna inkluderas i utveckling/design av framtida studier.

## List of papers

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

- I. Åsberg Johnels, J., Carlsson, E., Norbury, C., Gillberg, C., & Miniscalco, C. (2018). Current Profiles and Early Predictors of Reading Skills in School-Age Children with Autism Spectrum Disorders: A longitudinal, retrospective population study. *Autism*, Published online 7 Dec.
- II. Carlsson, E., Miniscalco, C., Gillberg, C., & Åsberg Johnels, J. (2018). Assessing False-Belief Understanding in Children with Autism Using a Computer Application: A Pilot Study. *Journal of Psycholinguistic Research*, 1–15.
- III. Carlsson, E., Åsberg Johnels, J., Gillberg, C., & Miniscalco, C. Narrative Skills in Primary School Children with Autism: Relation to Language and Nonverbal Event Sequencing. *Manuscript*.
- IV. Carlsson, E., Miniscalco, C., Kadesjö, B., & Laakso, K. (2016). Negotiating knowledge: parents' experience of the neuropsychiatric diagnostic process for children with autism. *International Journal of Language & Communication Disorders*, 51: 328–338.

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### **Abbreviation**

ADHD Attention-Deficit/Hyperactivity Disorder ADOS Autism Diagnostic Observation Schedule

ASD Autism Spectrum Disorder

ASSQ Autism Spectrum Screening Questionnaire
AUDIE AUtism Detection and Intervention in Early life

BST Bus Story Test

CELF-4 Clinical Evaluation of Language Fundamentals – 4

CHC Child Health Centre

CNC Child Neuropsychiatry Clinic
DLD Developmental Language Disorder

DSM Diagnostic and Statistical Manual of Mental Disorders

ESSENCE Early Symptomatic Syndromes Eliciting Neurodevelopmental

Clinical Examinations

FB False Belief understanding
GDS Griffiths´ Developmental Scales
IDD Intellectual Disability Disorder

IQ Intelligence Quotient LD Language Disorder

RDLS Reynell Developmental Language Scales III

PPVT III Peabody Vocabulary Test III SLP Speech and Language Pathologist

ToM Theory of Mind

TROG-2 Test for Reception of Grammar – 2 VABS Vineland Adaptive Behavior Scales

ABBREVIATION 10

### Introduction

Language and communication development are fundamental aspects of a child's development that are intertwined with cognition, social development and world knowledge. Children with autism spectrum disorders (ASD) have problems with communication as a "core" symptom, and late language development or loss of language skills are common reasons for parents to seek help.

This thesis will describe and explore literacy, theory of mind and narrative ability – all of which are aspects of communication – in children with ASD. It will also address questions of both theoretical and clinical relevance, as informed by the research fields of ASD, reading research, and speech and language research. A major theme throughout the thesis is an attempt to relate the findings to linguistic capacity as measured by language tests on the word and sentence level. Thus, the purpose is to try to understand in what way the communication difficulties that per definition are present in ASD are influenced by structural language ability. In addition to the focus of the first three substudies on the relationships between structural language abilities, other cognitive capacities and communicative functions in children with ASD, the thesis ends by the inclusion of a substudy of the children's parents' perspective on the diagnostic process and their child's development.

### Autism spectrum disorders

Autism spectrum disorder (ASD) is a congenital or early-acquired complex neurodevelopmental disorder characterised by difficulties in social interaction, impaired social communication and restricted behavioural patterns, also known as the 'triad of impairment' (Wing & Gould, 1979). In the most recent classification system, the DSM-5 (APA, 2013), social interaction and communication are no longer separated; instead the two are combined within 'deficit in social communication and social interaction' and the second main area of difficulties is 'restricted, repetitive patterns of behaviour, interests, or activities'. The symptoms must be present in the early developmental period, typically before age of 3 (but the symptoms may not become fully manifest until social demands exceed limited capacities), and usually persist throughout life (APA, 2013). According to DSM-5, cognitive and language level must be specified (APA, 2013), and a child could also receive diagnoses of coexisting disorders such as language disorder (LD) or attention deficit hyperactivity disorder (ADHD). In fact, DSM-5 highlights the association between LD and other neurodevelopmental disorders such as ASD, as

well as the association between LD and social communication (pragmatic) disorder

The prevalence of ASD in the general population is about  $0.8-2\,\%$  (Baird, Simonoff, Pickles et al., 2006; Coleman & Gillberg, 2012; Nygren et al., 2012). In the literature, the boy to girl ratio of ASD has often been suggested to be around 4:1 (Fombonne, 2009). The exact cause of any given child's ASD can only rarely be determined, but several risk factors have been established suggesting a complex hereditary condition that involves several genes and some environmental factors (Coleman & Gillberg, 2012). Several pre-, peri- and postnatal risk factors have been identified including certain intrauterine infections (e.g. brain infection from herpes, rubella, cytomegalovirus and toxoplasmosis), toxins (e.g. alcohol and valproate) and extreme prematurity (Coleman & Gillberg, 2012; Gardener, Spiegelman & Buka, 2009; Johnson & Myers, 2007).

ASD is hardly ever an isolated condition, as co-occurring and overlapping difficulties and symptoms are very common (Coleman & Gillberg 2012; Gillberg & Billstedt, 2000; Lundström et al., 2015; Gillberg, 2010; Gillberg & Fernell, 2014; Wing, 1997). Coexisting symptoms include learning disabilities, intellectual disability disorder (IDD), ADHD, epilepsy, developmental coordination disorder, tics, Tourette's syndrome, feeding or sleeping problems, digestive problems, visual and hearing difficulties and other psychiatric symptoms. Indeed, individuals without any 'comorbidity' may not always be recognised, since it is often ASD in combination with other symptoms that leads to impairment early in life (Gillberg, 2010). It has also become increasingly clear that there are no sharp boundaries between ASD and non-ASD cases; instead the phenotype appears on a continuum and autistic features, defined as having one or more of the characteristics associated with ASD, are in fact common in the general population (Posserud, Lundervold & Gillberg, 2006).

ASD is associated with differences in the way information is processed and how the surrounding world is comprehended. Individuals with ASD tend to show an inability to understand other people's feelings, thoughts and needs, or a lack of (social) imagination. Many display an obsessive interest in one subject, difficulty dealing with changes in routines, repetitive questioning and behaviour, poor planning and organisational skills and impairment in the use of non-verbal communication, and a substantial proportion of children with ASD also have speech and language difficulties (Coleman & Gillberg, 2012; Kjellmer, Fernell, Gillberg & Norrelgen, 2018). The degree of functional impairment varies greatly across individuals and the symptoms change over time. ASD is usually a lifelong condition, but an individual's function can change over time, in relation to their development in general just as for children and adolescents without ASD (Cohen & Volkmar, 1997). A valid diagnosis can often be made already at 18–24 months of age by a team of experienced professionals (Clark, Barbaro & Dissanayake,

2017; Chawarska, Klin, Paul & Volkmar, 2007). However, many children – particularly those with 'normal level' IQ – are not diagnosed until school age (Brett, Warnell, McConachie & Parr, 2016; Christensen et al., 2018).

### Early concerns

Early signs of ASD often appear in the first year of life, making the toddler years a crucial period to identify features of ASD. Delayed speech and language development is a common reason parents seek referral and clinical examinations of their child in the first place (Dahlgren & Gillberg, 1989; De Giacomo & Fombonne. 1998). Moreover, these children often show early regulatory difficulties with e.g. sleeping, feeding and excessive crying (Barnevik-Olsson, Carlsson, Westerlund, Gillberg & Fernell, 2013). There is a widespread consensus regarding the importance of identifying children with ASD as early as possible, and great efforts have been made accordingly (Barbaro & Dissanayake, 2009; Gillberg, Ehlers & Schaumann, 1990; Fernell, Eriksson & Gillberg, 2013; Kantzer, Fernell, Gillberg & Miniscalco, 2013; Zwaigenbaum et al., 2015). Still, many of the identified early signs are not necessarily ASD specific, but instead relate broadly to neurodevelopmental differences. Such early symptoms have been referred to as Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations (ESSENCE) (Gillberg, 2010). ESSENCE is an umbrella term for early (presenting before age 3-5 years) life symptoms (Gillberg, 2010). Children with early ESSENCE symptoms usually end up meeting the criteria for one or (usually) several developmental disorders such as ASD, LD and/or ADHD later on (Gillberg, 2010; Ozonoff et al., 2010; Wetherby et al., 2004).

ESSENCE symptoms in children can be identified through speech and language screening (Law, Boyle, Harris, Harkness & Nye, 2000; Miniscalco, 2007) and ASD screening programs (Baron-Coen, Allen & Gillberg, 1992; Nygren et al., 2012). As previous research has shown that speech and language difficulties in ASD are associated with a worse prognosis (Billstedt, 2007) identification of children with ASD at risk of poor outcome is essential, and should involve a consideration of language and communication. Few longitudinal studies of screened populations provide evidence of benefits and/or drawbacks associated with these screening procedures (Fernell, Eriksson & Gillberg, 2013).

Parents' views of the diagnostic process are of great importance (Mindence & O'neill, 1999), yet only a limited number of studies of clinically referred families whose children were identified by screening have been carried out. This shortcoming will be explored further in this thesis (Study IV). Studies from the UK have shown that parents' experiences and overall satisfaction with the diagnostic process vary, depending on the age at which the child was diagnosed, with parents of children who are older at this point being less satisfied (Crane et al., 2016; Howlin & Moore, 1997). Parents of children with ASD experience stress in their

everyday life (Corcoran, Berry & Hill, 2015; DePape & Lindsay, 2015; Ooi, Ong, Jacob & Khan, 2016) and some studies report insufficient care and support (Westman Andersson, Miniscalco & Gillberg, 2017; DePape & Lindsay, 2015; Ooi et al., 2016). Ello and Donovan (2005) studied families raising a child with a developmental disability and showed that the level of total parenting stress within families decreased significantly when the child's functional communication improved after participating in a family intervention program. The family is a central arena for the socialisation of language and communicative development for children (Rowland, 2013) which make parents and the family are key partners in therapeutic programmes for children with ASD (Zwaigenbaum et al., 2015). Thus, there is a need to examine child abilities and parental perspectives in the same project, as is done in the current thesis

### Cognitive theories in ASD research

Several theories attempt to explain the underlying mechanisms that lead to the behaviours that define the disorder, of which two are of particular interest in relation to the focus of this thesis: the theory of mind deficit and weak central coherence.

### Theory of Mind

Over the years, researchers within the field of ASD have focused on the theory of mind deficit (ToM or 'mentalising') which refers to a weakness in the socio-cognitive capacity of understanding that other people think and behave on the basis of mental states (Premack & Woodruff, 1978). ToM has a strong impact on social communication and pragmatic language ability, and has been shown to be particularly difficult for many individuals with ASD. Early in development, ToM deficits may cause the child to be unaware of other people's feelings or/and to act egocentrically. Later on, it manifests as an inability to understand what other people are thinking or to interpret the way people act (Baron-Cohen, Leslie & Frith, 1985; Frith, 1989; 2003). ToM has implications for many aspects of individuals' functioning, including social competence (Astington & Jenkins, 1995), pragmatic language skills, peer acceptance (Dunn, 2000; Dunn & Cutting, 1999) and early success in school (Astinton & Peltier, 2005; Derks et al., 2016). ToM is often assessed by means of false belief understanding tasks (FB) (Wimmer & Perner, 1983). The issue of ToM deficits in ASD will be of importance in Study II, where I examine how verbal support and structural language ability are related to ToM assessed as FB understanding in children with and without ASD.

#### Weak central coherence

Another aspect of cognition in ASD that could be understood as a cognitive style is that of weak central coherence (Frith, 1989; 2003; Happé & Frith, 2006). The weak central coherence theory posits that individuals with ASD have a strong focus on select features and details while being relatively poor at seeing the big overall picture. Weak central coherence is thus characterised by a bottom-up manner of processing incoming stimuli (Happé & Frith, 2006). According to Frith (Frith, 1989; 2003), this theory is not meant to alone explain the difficulties seen in ASD, but rather in combination with other cognitive aspects, e.g. ToM deficits. Moreover, the theory potentially accounts for certain strengths of ASD cognition. Indeed, individuals with ASD sometimes develop certain abilities as a consequence of their attention to details, which can lead to an advantage in certain activities where such skills are important. There is no consensus regarding the best way to assess central coherence. According to Happé and Frith (2006), weak central coherence can be reflected in certain profiles of neuropsychological test scores, e.g. higher scores on 'Block Design', and 'Matrices' and in a poor performance on 'Comprehension' and 'Picture Arrangement' (WISC-III, Wechsler, 1999). I will deal with the issue of weak central coherence in relation to narrative retelling ability in ASD in Study III of the thesis.

# Communicative development and language disorders in ASD

Unique to us humans is the ability to use language, a complex system of conventional symbols. Language is multifactorial and comprises several subsystems. Cognitively, language could be divided into and explained in terms of two broad categories; *structural language abilities* and *functional communication abilities*, see Figure 1 (Pennington, 2008). *Structural language abilities* comprise phonology (speech sound processing), grammar/syntax and semantics. *Functional communication abilities* refers to pragmatics and discourse processing, i.e. the conventions and principles regarding how language is used in context. These abilities involve the understanding of social rules in conversation such as turn taking, staying on the topic and by confirming with the conversation partner during conversation. The term also refers to abilities beyond word and sentence level in communication, i.e. those involving a need to understand and produce narratives and explanations. Functional language difficulties are more or less by definition a core symptom in ASD (APA, 2013)

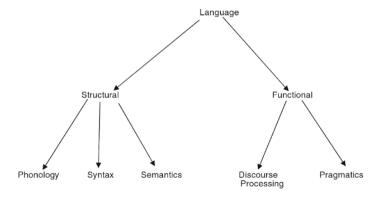


Figure 1. Cognitive analysis of language in terms of structural and functional language. Pennington. (2008) Diagnosing Learning Disorders, Second Edition: A Neuropsychological Framework. Chapter 2, p. 20. Reprinted with permission from © Guilford Press.

Children with ASD are often identified as in need of neurodevelopmental assessment due to their delay in language milestones. Parents finding it difficult to get the child's attention and a child seeming unresponsive to their name being called or someone communicating with them are examples of early communicative difficulties (Lord, 1995; Osterling, Dawson & Munson, 2002), Lack of or deviant babbling during the first year of life (Luyster, Seery, Talbott & Tager-Flusberg, 2011; Oller, Eilers, Neal & Schwartz, 1999) or that the babbling might not be used in a communicative way are other possible signs. In fact, children later diagnosed with ASD have been found to demonstrate significantly lower levels of canonical babbling than peers without ASD, suggesting that little or no canonical babbling could be a very early sign of ASD (Paul, Fuerst, Ramsay, Chawarska & Klin, 2011). Many children with ASD show delays and a slower development rate in speech acquisition compared with peers without ASD, saying their first words at 24 months (12 months delayed) and producing their first sentences at 48 months (18-24 months delayed) (Howlin, 2003; Tager-Flusberg, Paul & Lord, 2005; Gernsbacher, Morson & Grace, 2015).

Some toddlers (10–25%) with ASD regress, lose or suddenly deaccelerate in language skills/development (Barger, Campell & McDonough, 2013; Fernell et al., 2010; Kantzer et al, 2013; Thompson et al., in press). The language regression usually appears during the second year of life, with reports of both losses in productive language use and more subtle decreases in vocalisations and social communication (Lord, Schulman & DiLavore, 2004; Ozonoff et al., 2010). Regression in language skills seems to be a unique marker of risk for ASD (Lord et al., 2004).

Echolalia (immediate or delayed) is another autism-related sign of differences in speech and language development (Charman & Stone, 2006; Tager-Flusberg et al., 2005). It has been suggested that both types of echolalia can serve communicative purposes for the speaker (Tager-Flusberg et al., 2005); indeed, at an early stage of language development, this may be the only way in which the child can actually produce speech. Echolalia is however not a unique feature of all individuals with ASD or that appears exclusively in individuals with ASD, but when it occurs in children without ASD it usually does not persist as long. Tager-Flusberg and Calkins (1990) found that, over the course of development, echolalia rapidly decreased also in children with ASD.

In ASD, difficulties with social communication and pragmatic language, i.e. difficulties using language in a social context, are universal features (APA, 2013: Baird & Norbury, 2016: Frith, 1989: 2003: Stirling, Douglas, Leekam & Carey, 2014). The tendency of individuals with ASD to perceive what others say in a different way is an example of such pragmatic language difficulties (Tager-Flusberg & Anderson, 1991). They usually have difficulties with understanding metaphors, humour and irony, and often use deviant intonation and prosodic features (Tager-Flusberg et al., 2005). They may also show communicative difficulties in interaction by shifting topics abruptly and providing novel information without first establishing common ground with the communicative partner. In addition, individuals with ASD often provide fewer initiatives and are less responsive to the conversation partner (Ying Sng, Carter & Stephenson, 2018). These communicative patterns make it difficult for individuals with ASD to establish and maintain mutuality in conversation (Tager-Flusberg et al., 2005). Difficulties in such communicative patterns are also evident – and perhaps even more salient – in individuals with ASD who have intact structural language abilities.

#### Language ability and language disorder in ASD

The literature points to great diversity in language development and competencies among people with ASD, the documented heterogeneity is probably partly due to the variability in competencies and partly to different studies having focused on different groups of people with ASD (Gernsbacher et al., 2015). Some children with ASD show good (or even superior) structural language abilities in formal testing, with vocabulary and sentence structure scores above what could be expected for their age (Boucher, 2012), while others show language disorder (LD) i.e. by demonstrating structural language difficulties similar to those in developmental language disorder (DLD) (Kjellmer et al., 2018; Tager-Flusberg & Joseph, 2003). There is considerable heterogeneity in the extent to which difficulties with structural language co-occur in ASD, and a range of language domains may be impacted (Brignell et al., 2018; Eigsti, de Marchena, Schuh & Kelley, 2011). A recent study by Kjellmer et al. (2018) examined language ability in 83 children (4–6 years-old) with ASD but without IDD and found that more than 60% of the

children had moderate to severe structural language problems, defined as impaired performance on two or more language measures (in total six measures), while only one in six had no such problems.

Most individuals with ASD develop speech; in studies of individuals included from population-based samples of pre-schoolers between 15- 30% of children with ASD were minimally verbal or nonverbal (i.e. had little or no speech) (Anderson et al., 2007; Norrelgen et al., 2015). All of the children in the study by Norrelgen et al. (2015) who were classified as nonverbal or minimally verbal had IDD

Studies have reported that impaired receptive language is common in ASD (Charman, Drew, Baird & Baird, 2003; Kjellmer et al., 2018; Kover, McDuffie, Hagerman & Abbeduto, 2013; Loucas et al., 2008; Norrelgen et al., 2015), but also that toddlers with ASD have smaller expressive vocabularies than same-age peers (Charman et al., 2003; Miniscalco, Fränberg, Schachinger-Lorentzon & Gillberg, 2012). Other studies have shown that receptive language is more impaired than expressive language (Charman et al., 2003; Ellis Weismer, Lord & Esler, 2010; Hudry et al., 2010), whereas others have found the opposite pattern (Luyster, Kadlec, Carter & Tager-Flusberg, 2008). Further, early receptive language ability and IQ have been found to be important for future vocabulary development (Brignell, May, Morgan & Williams, 2018). The research into syntactic development in ASD has been conflicting. Whereas most studies have found a clear delay in syntactic development (Egisti, Benetto & Dadlani, 2007; Egisti et al., 2011), one showed no significant difference (Shulman & Guberman, 2007).

Expressive phonology has often been considered a relative strength in ASD compared with other language skills (Bartak, Rutter & Cox, 1975; Kjelgaard & Tager-Flusberg, 2001). However, when Kjelgaard & Tager-Flusberg (2001) subgrouped a fairly large sample with ASD, children who presented with impaired structural language (on tests) also showed difficulties with phonological processing measured with non-word repetition. Other studies have shown more widespread difficulties in regarding phonology and that approximately 30% children present with speech difficulties in addition to other structural language difficulties (Kjellmer et al., 2018; Shriberg, Paul, Black & Van Santen, 2011). In Kjellmer et al. (2018), only around 4% of the included children displayed expressive phonological difficulties without difficulties in any other language domain.

Subgrouping into different language profiles is a commonly used method to capture the heterogeneity in language skills among children with ASD (cf. Kjellgaard & Tager-Flusberg, 2001; Norbury, 2005; Tager-Flusberg & Joseph, 2003). Using this approach, results confirm that there is an identifiable subgroup of children with ASD who have LD in addition to their autistic presentation. A child with ASD can consequently get an additional LD diagnosis (DSM-5, APA, 2013). Lindgren et al. (2009) found no significant correlations between language and ASD severity. In that study, the children with ASD were subgrouped into ASD

(average language) and ASD (LD) and then compared with children with DLD. The results show that while the children with ASD (average language) scored higher than both other groups on most assessments, no difference was seen between children with ASD (LD) and those with DLD except for the higher performance by the ASD (LD) group on a subtest within a reading battery. The DLD and ASD (LD) groups also had lower non-verbal IQ, phonological processing, lexical comprehension and reading abilities than the ASD (average language) group (Lindgren, Folstein, Tomblin & Tager-Flusberg, 2009). Thus, the language problems seen in some children with ASD seem to often resemble language problems of children with DLD (Tager-Flusberg, 2015).

Developmental trajectories are also important to consider. The prognosis for language outcomes among individuals with ASD was studied in a recent systematic review and meta-analysis (Brignell et al., 2018). The authors concluded that children with ASD under the age of 11 on average develop at a rate comparable to age-expected norms or even faster, i.e. with a tendency to 'catch up' over time. Still, there are few population-based studies and studies where children are followed from the toddler and preschool years up to school age and beyond (Brignell et al., 2018). It would be valuable to know more about the trajectories throughout life, since these individuals might need more and specific intervention to deal with language difficulties (Tager-Flusberg et al., 2005). Although largely outside the scope of the current thesis, I touch upon this issue in Study I.

### Narrative ability in ASD

Storytelling was widespread long before literacy emerged. The narrative ability reflects our ability to dress our thoughts and experiences in words and to convey events by using language in communicative situations (Bruner, 1986). Narrative development starts early in life and is entangled with cognition, social development, linguistic skills and world knowledge (Leinonen, Letts & Smith, 2000). The capacity develops over time and has implication for many aspects of children's development, such as planning, organising and sequencing one's thoughts and the development of a sense of identity (Berman, 2009). Moreover, narrative ability is considered to be an ecologically valid way of capturing functional language in childhood (Botting, 2002). Narrative ability has shown to predict future communicative functioning and persistent language impairment (Bishop & Edmundson, 1987; Norbury & Bishop, 2003), social interaction (Pelletier & Wilde Astington, 2004), literacy and reading development (Cain & Oakhill, 1996; Stothard, Snowling, Bishop, Chipchase & Kaplan, 1998) as well as future academic achievement (Fazio, Naremore & Connell, 1996). In addition, there is a relationship between narrative and pragmatic ability (Reuterskiöld Wagner, 1999), and thus it is considered to be an important skill to assess in individuals with ASD (Baixulli, Colomer, Roselló & Miranda, 2016; Bruner & Feldman, 1993: Miniscalco, Hagberg, Kadesjö, Westerlund & Gillberg, 2007). When creating a story or retelling a story,

one needs to take the social context into account, organise information globally and use language efficiently. Thus, producing a narrative requires a multitude of skills, including linguistic, cognitive and social abilities (Botting, 2002; Norbury & Bishop, 2003). Consequently, narrating can be expected to be very difficult for children with ASD, irrespective of their language ability at sound, word and sentence level (structural language). But is this actually the case?

In a recent meta-analysis shows that children with ASD tell narratives that lack in syntactical and story structure, and they also present with a lower use of internal state language (i.e. language describing the characters' thoughts and emotions) (Baixiauli et al., 2016). It is unclear whether these results are specifically linked to ASD or to structural language skills (at the word and sentence level). When the children were matched very carefully on age, IQ, expressive and receptive language ability, the differences between children with and without ASD in story length and syntactic complexity were no longer significant (Diehl, Bennetto & Young, 2006; Peristeri, Andreou & Tsimpli, 2017). In contrast, other studies have reported conflicting results: children with ASD performed shorter and less complex sentences than both age- and language-matched non-ASD children (King, Dockrell & Stuart, 2013) and used fewer subordinate clauses in narratives (Peristeri et al., 2017). How narrative ability is related to structural language abilities in ASD is an important question addressed in the current thesis (Study III).

If the narrative difficulty in ASD cannot be fully explained by simultaneous language difficulties at the word and sentence level, then which additional factors might be involved in narrating, and can they be assessed separately from language ability? As for other variables of interest when explaining narrative performance, a previous study by our research team examined story retelling and its relation to language ability and nonverbal sequential reasoning using regression analysis. Specifically, nonverbal sequential reasoning – assessed using a picture arrangement task from WISC III (Wechsler, 1999; see Figure 2) – was suggested to constrain the ability to convey story information during oral narration in children with neurodevelopmental disorders (Åsberg Johnels, Hagberg, Gillberg & Miniscalco, 2013). Importantly for the current research question and with regard to ASD, the Picture Arrangement test is a nonverbal task where the test leader instructs the child to arrange a set of coloured pictures in the right order to produce a comprehensible story (Wechsler, 1999), and the child's performance has been suggested to reflect central coherence (Happé & Frith, 2006).







Figure 2. A set of pictures from the Picture Arrangement subtest in WISC-III. Printed with permission from © Pearson Sweden.

Narrative ability can be assessed by oral story retelling, a method that tends to be suitable for preschool children (Westerveld & Vidler, 2015) and both younger and older children with cognitive disabilities, as they generally produce longer and grammatically more complex narratives in story retelling narratives than in self-generated stories (Boudreau, 2008; Miles, Chapman & Sindberg, 2006). In the Bus Story Test (BST) (Renfrew, 1997), oral story retelling is assessed using picture support, which reduces the cognitive load since the pictures enable the child to remember the explicit content and do not require recalling past events (Liles, 1993).

### From language to literacy in ASD

When children grow older, literacy and reading development is an essential part of a child's development and is of great importance for academic achievements, independence and participation throughout life. Studies on reading in ASD have increased in number over recent years and show great diversity in reading capacity among children with ASD (Åsberg, Kopp, Berg-Kelly & Gillberg, 2010; Brown, Oram-Cardy & Johnson, 2013; Nation, Clarke, Wright & Williams, 2006; Norbury & Nation, 2011; White et al., 2006).

A generally accepted theory in reading research is that reading comprehension builds on a foundation of linguistic/listening comprehension (Hoover & Gough, 1990; Hulme & Snowling, 2009). In particular, the so-called 'simple view of reading' (S.V.R.) theory (Gough & Tunmer, 1986; Hoover & Gough, 1990) proposes that reading comprehension is a product of decoding skills and oral language/listening comprehension. Word reading (decoding) refers to the process of transforming printed letters/words into speech sounds that can be synthesised into words (Lundberg, 1978; 2002). With practice, this written word identification becomes increasingly automatised. Deficits in decoding/word reading have shown to be associated with difficulties in phonology (Høien & Lundberg, 2000; Svensson & Jacobsson, 2006). Specifically, poor access to phonological representations of words and/or poor phonology have been found to be associated with difficulties

in the area of decoding/word reading (Snowling & Melby-Lervåg, 2016), while deficits in reading comprehension have been found to be associated with deficits in both decoding and/or oral language comprehension (Hulme & Snowling, 2009).

There are earlier studies suggesting that reading comprehension is difficult for children with ASD, and in some cases even when they display sufficient or even enhanced word decoding (Brown et al., 2013; Davidson & Ellis Weismer, 2014). These prior findings suggest that a close association between oral language and literacy skills can be expected in children with ASD. This is an important topic addressed in the current thesis (Study I).

The discrepancy between strong decoding skills and weak reading comprehension that has been found in some individuals with ASD is sometimes referred to as *hyperlexia* (Aron, 2012; Grigorenko, Klin & Volkmar, 2003; Huemer & Mann, 2010; Nation, 1999; Newman et al., 2007; Ostrolenk, d'Arc, Jelenic, Samson & Motton, 2017). Grigorenko et al. (2003) suggest that about 5–10% of children with ASD display this pattern. Hyperlexia could be described as a dissociation between phonological and non-phonological language skills that may explain why these children are able to develop skilled word reading while failing to develop age-appropriate reading comprehension (Bishop & Snowling, 2004). Some children with ASD have an early interest in letters and numbers, and some learn to read without any formal instructions (Loveland & Tunali-Kotoski, 1997).

The subgrouping procedure used to characterise heterogeneity in oral language has also been used in reading research for children with ASD. In a study by Nation et al. (2006), different subgroups were described based on age-referenced test scores. A first group included children with generally poor reading skills, a second group performed well on both word reading and text comprehension and a third group were poor at reading comprehension but had relatively stronger skills in decoding, confirming the idea that word recognition seems to be a relative strength in a sub-group of children with ASD (Davidson & Weismer, 2014; Norbury & Nation, 2011; Ricketts, Jones, Happé & Charman, 2013). Furthermore, some studies have reported an association between increased ASD symptoms and reduced reading comprehension, suggesting that poor reading comprehension in children with ASD may reflect underlying difficulties in social communication (Åsberg et al., 2010; McIntyre et al., 2017; Ricketts et al., 2013; Westerveld et al., 2017).

Two previous studies use a longitudinal approach (Davidson & Weismer, 2014; Miller et al., 2017) to explore predictors of reading outcome in preschoolers with ASD. Both concluded that oral language skills provide a base for later reading comprehension, and the results showed that other early predictors (non-verbal cognitive ability and autistic severity) also influenced the results. Yet, none of these longitudinal studies applied a subgrouping procedure. Furthermore, previous ASD reading research based on convenience and/or clinical samples with the exception of one population-based sample in the studies by Jones et al. (2009) and

Ricketts et al. (2013). Hence, there is a need for longitudinal population-based studies. Study I of the current thesis aimed to fill several gaps in the literature in these regards.

# Theory of mind – the relation to language ability in ASD

Social communication is a core difficulty in individuals with ASD, and ToM deficits is considered to be of importance when trying to explain those difficulties. The ToM deficit will affect an individual's ability to take the perspectives of others, which affect the social interaction with others and could lead to communicative misunderstandings (Frith, 1989, 2003; Happé, 1995). One commonly used way of assessing this ability is by testing false belief understanding (FB) developed by Wimmer and Perner (1983) and then further refined by Baron-Coen et al (1985) by means of the now well known 'Sally-Anne' test (see Figure 3).

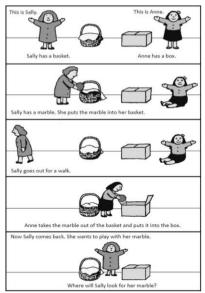


Figure 3. A description of the false belief test 'Sally-Anne' from Explaining the Enigma (Frith, 2003). If a child that is presented with this FB-understanding scenario says that Sally will look for the ball in the basket where she placed it (although it is now physically located somewhere else) the child is credited with false belief understanding/theory of mind". Printed with kind permission from © John Wiley and Sons.

Over the years, several studies have examined the relation between FB and language and showed that FB is coupled with language ability in both typically developed children and clinical groups (de Villiers & Pyers, 2002; Dunn, Brown, Slomkowski, Tesla & Youngblade, 1991; Lohmann & Tomasello, 2003; Loukusa, Mäkinen, Kuusikko, Gauffin, Ebeling & Moilanen, 2014; Meristo, Hjelmquist & Morgan, 2012; Miller, 2006; Rakhlin et al., 2011). Furthermore, having a 'language' to talk about the mind, i.e. a meta-language based on mental verbs such as 'knows' and 'thinks', is suggested to be of importance for the development of ToM (Olson, 1989). The impact of syntactic language abilities on FB understanding has also been particularly well studied, and it has been suggested that syntactical skills opens up necessary representational space for FB processing (de Villiers & de Villiers, 2000; de Villiers & Pyers, 2002). At the same time, there is no consensus about a possible causal relation between structural language and ToM (Miller, 2006). The strength of this effect might also depend on how FB is measured and which language skills are in focus.

The association between FB and language ability has been observed in ASD as well: children with more advanced language skills tend to perform better on tasks tapping into ToM (Happé, 1995). It has also been hypothesised that people with ASD and strong language skills solve ToM tasks in an unusual way, both more consciously and more logically and that this is done in a verbally mediated manner (Happé, 1995, p. 852). One hypothesis is that all individuals with ASD do in fact struggle with ToM tasks, but that some utilise language-based compensatory strategies to solve it successfully. To investigate the role of language in FB processing. i.e. whether the FB understanding is verbally mediated. Forgeot d'Arc and Ramus (2011) used a novel approach. They explored FB performance in adults without ASD using a verbal shadowing technique when presenting FB scenarios in several conditions, with the point being to isolate the effect of having linguistic information available during FB processing. The results for these typically developed adults indicate that the linguistic interference decreased the overall inference-making ability, but not specifically explicit false belief attribution. How may such manipulation of language support affect the FB performance of children with ASD? One possibility is that an attempt to block access to language mediation during the presentation of an FB scenario will reveal ASD-related difficulties in FB more clearly, and that this is the case even in children with a stronger structural language ability. The issue of FB understanding in ASD, its association with structural language ability and the potential role of language support is studied further in Study II of this thesis.

### Summary of the introduction

Impaired communication is a core symptom in individuals with ASD, yet the number of studies of other aspects of language skills and developmental trajectories in individuals with ASD has increased in recent years, suggesting the necessity to assess not only (social) communication but also structural language, i.e. phonology, semantics and grammar, and to follow the development over time. This thesis entailed a longitudinal perspective of language, literacy development and broader social communicative abilities in 7–8 year old children with ASD recruited from an early screening. It adds to our knowledge about the association between structural language skills and complex communicative functions in children with ASD – specifically aspects of literacy and narrative ability and false belief understanding. The insider perspective was also included in an attempt to take the parent perspectives of having a child go through early screening and the neuropsychiatric diagnostic process into account, and to highlight the importance of taking parent concerns seriously.

### Aims

The main aim was to investigate literacy, 'theory of mind' and narrative ability – i.e. aspects of communication – in children who had screened positive for autism spectrum disorders (ASD) and to relate the findings to linguistic capacity as measured by language tests at the word and sentence level. Another aim was to explore the parent experiences of having a child go through the ASD screening and the diagnostic process.

The thesis entails four substudies and the specific aims of the thesis were:

- I. To identify early and concurrent correlates of reading profiles in children who had screened positive for ASD as toddlers and been followed up at early school age.
- II. To understand how verbal support influences the FB understanding performance in children with and without ASD assessed with an interactive computer tablet.
- III. To describe oral narrative ability in children with ASD by using group comparisons and to determine how it relates to structural language ability at word and sentence level as well as non-verbal cognitive abilities in ASD.
- IV. To investigate parent perspectives the lived experiences of having a child going through the neuropsychiatric diagnostic process.

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### Methods

A wide range of (several different/a variety of) test instruments, material, and methods were used in Studies I–III. In Study IV, a qualitative i.e. a phenomenological hermeneutic method, was used. Details of the studies are described below.

### Participants and procedure

All participating children and parents in the present thesis were recruited from a general ASD screening at age 2.5 years at the public child health care centres (CHCs) in Gothenburg, i.e. *AUtism Detection and Intervention in Early life*, or the AUDIE project (Nygren et al., 2012), which targets >95% of all eligible children (Arvidsson, Holmberg, Reuter & Strömbom, 2010).

All children who screened positive for ASD (the AUDIE cohort) were referred to the Child Neuropsychiatry Clinic (CNC), which is a local, regional and nationwide clinic for neuropsychiatric assessment. In total, 129 children screened positive during a 2-year period, and the parents of 107 children gave their consent to participate in the research project. The children were assessed at age 3 years (on average 2.9 years) (T1) by a multidisciplinary team consisting of a child and adolescent psychiatrist, a neuropsychologist, a special educator and a speech and language pathologist (SLP) (Kantzer et al., 2013). The children were followed up at age 5 (T2) (n=96) (Kantzer, Fernell, Westerlund, Hagberg, Gillberg & Miniscalco, 2018).

The parents of 11 children were recruited at the T2 follow-up to participate in interviews held by the author (see Table 1). These interviews focused on how they had perceived the diagnostic process performed two years earlier. Each interview was audio-recorded and lasted for 45–120 minutes. The interviewer followed a semi-structured question guide developed together with the co-authors. The author was neither employed at the clinic at the time of the interviews, nor involved in any way in the assessments that the families had gone through. After nine interviews, the respondents did not bring up any new subjects or information, and thus, a decision was made to conduct just a few more interviews and if no relevant new information would surface, the data collection would stop. Consequently, the collection of information was ended after the 11<sup>th</sup> interview, as it was determined that data saturation had been reached suggesting that data saturation was reached, i.e. no new understandings (themes relevant in relation to the aim of the study) emerged (Creswell, 1994; Creswell & Poth, 2017).

At a third point in time (T3), 85 children (15 girls and 70 boys) of the original 107 children, on average 7.5 years old (range 5.9–9.8) were assessed by two SLPs at CNC. The attrition rate from the T1 (age 3 years) to the T3 (age 7.5 years) assessment was 21%. Of these 85 children, 71 met full ASD criteria according to the *Diagnostic and Statistical Manual of Mental Disorders* (APA, 4th ed.; DSM-IV), based on all available information. It is important to note that all children showed autistic traits. Of the 85 included children, 12 (14%) needed an interpreter at T1 (assessment at 3 years); no child needed an interpreter at the T3 assessment.

Of the 85 assessed children at the 7.5 year follow-up, 67 (78%) went to elementary school, 14 (17%) went to special needs comprehensive school (*grundsärskolor* in Swedish) and four (5%) were in preschool. Table 1 gives an overview of the participants in the four studies.

In Studies II and III, a comparison group consisting of 106 children without ASD (53 girls and 53 boys; mean age 7.3 years; range 3.9–9 years) was included. All parents of the included children completed a background data questionnaire inquiring about e.g. the child's gender, age, language background, medical conditions and whether the child had had any SLP contact. To be included in the comparison group, a child could not have a known ASD diagnosis and needed to score above 70 on the Test for Reception of Grammar-2 (TROG-2) (Bishop, 2003). The author and SLP students (in their final year of study) recruited the participants from one preschool and three elementary schools (grades 0–2) in the greater Gothenburg region in Sweden using convenience sampling.

Table 1. Design of the four studies and age and gender of participants

Study	Design	Participants	Age (mean) years	Gender
I	Longitudinal study	53 children screened positive for ASD	6.6 – 9.8 (8.0)	♀ = 8; ♂ = 45
II	Experimental study Comparison group	68 children with ASD 98 CAM children	5.9 – 9.1 (7.5) 5.2 – 9.0 (7.5)	
Ш	Cross sectional Comparison groups	<ul><li>45 children with ASD</li><li>27 LM children</li><li>47 CAM children</li></ul>	5.9 – 9.8 (7.6) 3.9 – 8.6 (6.1) 6.5 – 9.0 (7.8)	
IV	Qualitative study	11 parent interviews*	30 - 46	9 = 6; 3 = 6

Note: LM = younger children matched on receptive language ability, CAM = matched on chronological age, \* parents of children included in the thesis, all of whom screened positive for ASD at age 2.5 years and were followed up 2 years after the first assessment.

### Material

Table 2 gives an overview of the test instruments and material used in Studies I-III

Table 2. Test materials used in the thesis for study I-III

Assessed ability	Test material	Study
Receptive grammar	Test of Reception of Grammar-2 (TROG-2)	I, II, III
	(Bishop, 2003) Reynell Developmental Language Scales III (RDLS) (Edvards et al., 1997)	I
Vocabulary	Peabody Picture Vocabulary Test (PPVT) (Dunn & Dunn, 1981)	I
Expressive language	The PARIS scale	I
Sentence repetition	Recalling Sentences (CELF-4) (Semel et al., 2003)	I, II, III
Oral non-word repetition	Non-word repetition (Radeborg et al., 2006)	I
Narrative ability	The Bus Story Test (BST) (Renfrew, 1997; Svensson & Touminen-Eriksson, 2000).	III
Letter knowledge/recognition	Umesol (24 letters, lower- and uppercase form) (Taube et al., 1984)	I
Decoding	Word reading (decoding) LäST (Elwér et al., 2009)	I
Reading comprehension	The DLS BAS-test (Järpsten, 2004)	I
Theory of mind	False belief understanding measured with a computer app (I-pad) (Åsberg et al., not published)	II
Autism severity & symptomatology	Autism Spectrum Screening Questionnaire (ASSQ) (Ehlers et al., 1999)	I, II,III
	The Autism Diagnostic Observation Scale Generic (ADOS) (Lord et al., 2000).	I, II
Adaptive behaviors	Vineland Adaptive Behaviors Scales (VABS), (Sparrow et al., 2005)	I
Non-verbal cognitive ability	WASI sub-test Matrices (Wechsler, 1999)	I, II, III
	Griffiths' Developmental Scales (Alin-Åkerman & Norberg, 1991)	I
Nonverbal sequential reasoning	Picture Arrangement (WISC III) (Wechsler, 1999)	III

Test instruments and materials used for the 3-year assessment in Study I

#### Language assessment

Language comprehension was assessed using the Reynell Developmental Language Scales III (RDLS) (Edvards, Fletcher, Garman, Hughes & Letts, 1997), which has Swedish norms (Eriksson & Grundström, 2000; Lindström & Åström, 2000). In addition, each child's expressive language level was rated by the SLP on a 1–5 scale using the 'PARIS schedule' (Philippe, Martinez, Guilloud-Bataille, Gillberg, Råstam et al., 1999), where 1 = no words at all; 2 = a few single words; 3 = a few communicative sentences; 4 = talks a great deal, mostly echolalia and 5 = talks a great deal, mostly in a communicative fashion.

#### Neuropsychiatric and neuropsychological assessment

A clinical child neuropsychologist assessed the children's general cognitive/developmental level using the Griffiths' developmental scales (GDS) (Alin-Åkerman & Norberg, 1991). The test included six subscales, the total score of which provides a developmental quotient (around M=100, SD=15).

The Autism Diagnostic Observation Schedule – Generic (ADOS) (Lord, Risi, Lambrecht, Cook, Leventhal & DiLavore, 2000) is a standardised, semi-structured play-based tool for assessment of communication, reciprocal social interaction, play and behaviour. Either module 1 or 2 was administered, based on the expressive language level of the child, and calibrated severity scores were calculated based on the resulting data (scores from 1 to 10) (Hus, Gotham & Lord, 2014). Higher scores indicated increased autistic symptom severity.

The communication and socialisation domains of the Vineland Adaptive Behaviour Scales (VABS) (Sparrow, Cicchetti & Balla, 2005) were administered by a child neuropsychologist during a face-to-face interview with one or both parents. Results were expressed in standard scores around a normative M=100 and SD=15.

# Test instruments and material used for the 7.5-year assessment in Studies I-III

#### Structural language tests (Studies I–III)

Language comprehension (receptive grammar) was assessed using the TROG-2 (Bishop, 2003, Swedish version 2009). The child was to match orally presented sentences with the correct picture of a choice of four. The results were presented as both raw scores (number of correctly solved blocks out of a maximum of 20) and standard scores (M = 100, SD = 15) based on Swedish norms.

The Recalling Sentences subtest from the Clinical Evaluation of Language Fundamentals -4, CELF - 4; (Semel, Wiig & Secord, 2003; Swedish version, 2013) and the results of the subtest were used as a language skill index that also includes a productive component (Klem, et al., 2015). 'Recalling Sentences' consists of 24 sentences. In the test, the child is to repeat each sentence produced by the test leader, resulting in a score from 0 (> 4 errors) to 3 (no errors), for a maximum score of 72. The results were presented as raw scores and scaled scores around a normative M = 10 and SD = 3, based on Swedish norms.

To assess receptive vocabulary, the Peabody Picture Vocabulary Test – Third Edition (PPVT-III; Dunn & Dunn, 1997) was used. Here, the child listened to a word uttered by the SLP and then selected one of four pictures that best described the meaning of the word. The test was not standardised for Swedish children, and therefore the original US norms were used.

In Study I, phonology/non-word repetition was assessed by asking the child to repeat thirty I-5 syllable non-words after the SLP presented them (Radeborg, Barthelom, Sjöberg & Sahlén, 2006). The SLP transcribed the responses using broad phonetic transcription according to the International Phonetic Alphabet (IPA, 2005). Each repeated non-word was scored as correct or incorrect.

#### *Oral narrative ability* (Study III)

The Bus Story Test (BST) was used to assess the child's ability to recall a story with the support of 12 colour pictures (Renfrew, 1997; Swedish version, Svensson & Tuominen-Eriksson, 2002). The SLP read the story and then the child was asked to retell the story while looking at the pictures. All stories were audio recorded and orthographically transcribed according to the Swedish manual. The test included three subscores: 1) Information (max = 54), 2) Subordinate Clauses, i.e. number of produced subordinate clauses in the retold story, and 3) Sentence Length, i.e. number of words in the five longest sentences divided by five. There are Swedish norms for children in the 3.9–8.5 age range, which did not fully cover the age range in the present study.

#### Reading assessment (Study I)

To examine the participants' single word reading/decoding ability the LÄST test was used (Elwér, Fridolfsson, Samuelsson & Wiklund, 2009). The child was asked to read as many words as possible in 45 seconds from a list of words. The test was then repeated using another list of words. A total score was created by adding the number of correctly read words from the two lists. Such word reading efficiency measures are typically used in Sweden and other semi-consistent orthographies. Swedish norms based on stanine (Standard nine) for each grade level are available in the LÄST manual.

Reading comprehension was assessed using the DLS BAS-test (Järpsten, 2004) in order to assess the child's ability to understand written sentences and narratives.

The DLS BAS-test comprises 20 sentences intertwined into a small story. For each sentence, the child is expected to mark the one picture out of five that best corresponds to the written content. The child is asked to read as many sentences as possible in 7 minutes (for 7-year-old children, i.e. first grade in Sweden) or in 5 minutes (for 8-year-old children, i.e. second grade in Sweden). The max score is 20. Swedish norms based on stanine (standard nine) for each grade level is available in the test manual

The child's letter knowledge was conducted by using Umesol (Taube, Tornéus & Lundberg, 1984) where the child is asked to name the letters of the Swedish alphabet (same as the English alphabet plus three additional), written on two sheets of paper in both upper- and lowercase form. The max score for each form is 24.

#### *False belief understanding (FB)* (Study II)

We used an "app" on a computer tablet that was developed by to the research group to explore first-order FB understanding based on change of location, and using the classic Sally-Anne test (Baron-Coen et al., 1985) as a model. The children were verbally instructed to watch and then answer questions about short films. Within the self-instructing intuitive application, there is a film clip of a modified Sally-Anne-like scenario featuring two characters: a woman ("Johanna") and a hand puppet ("Jansson the Cat") (both well-known names to Swedish speaking children). In the beginning of the clip, the child is verbally introduced to Johanna and "Jansson the Cat". "Jansson the Cat" moves a ball from the box that Johanna had put it in while Johanna is temporarily away. At the end of each trial, the child listened to questions within the application and responded by pointing (on the touch screen) to one of two yellow circles drawn around the two options (see Figure 4). Two questions were asked: the FB question 'Where will Johanna look for the ball?' and the control question 'Where is the ball really?'



Figure 4. A screen dump from the FB task with "Johanna" and "Jansson the Cat". The child answers the questions (i.e., "Where will Johanna look for the ball?" and "Where is the ball?") by pointing at one of the yellow circles on the touch screen.

In order to explore the effect of verbal/language support in FB task performance. film clip was shown in three different auditory conditions: 1) narrative. 2) silent. and 3) interference. In the narrative condition, the clip included a verbal description of the scenario given by a speaker voice within the application in much the same manner as Sally-Anne tests use to. In the *silent* condition, the clip was silent except for the questions at the end. In the *interference* condition, auditory interfering words were presented repeatedly in pseudo-random order, such as "ball." "box," "cat," "Johanna," and "Jansson,". The rationale for the interference condition was that we hypothesized that it would hinder to solve the task by using language ability for reasoning and that this condition might impair performance especially much in children with ASD and higher structural language ability. Two presentations of each condition were given in random order (randomized within the application), and the location of the ball was counterbalanced between presentations, i.e., in each of the three conditions one presentation had the ball placed in the left box and one presentation had the ball placed in the right box. The counterbalance of the locations demanded full attention to each presentation (rather than relying on answers to previous presentations). Each child needed about 3-4 minutes to complete the FB task. The child's responses were registered and saved within the application automatically.

### Non-verbal cognitive ability (Study I-III)

The matrices subtest of Wechsler abbreviated scales of intelligence (WASI) was used as a measure of non-verbal cognitive ability (WASI: Wechsler, 1999). Results were expressed in T-scores (M = 50, SD = 10) based on American norms. No Swedish norms were available.

Nonverbal sequential reasoning was assessed using the picture arrangement subtest from WISC-III (Wechsler, 1999). There are a total number of 14 sets within this subtest, in each set of cartoon pictures there are 3-5 pictures that form a short story event (see Figure 1). Correct sequencing of the pictures set within the time norm awards the child 2 points and 3 points extra points for speed. In keeping with instructions, the test was ended (after three failures. The results were presented in scaled scores around a normative mean of 10 (SD+3).

#### Autism symptomatology (Study I-III)

The Autism Spectrum Screening Questionnaire (ASSQ) (Ehlers, Gillberg, & Wing, 1999) was assessed for all participants' parents in the ASD group. ASSQ is a parent report measure used to measure autistic symptomatology. The questionnaire contains 27 items with a three-level Likert scale (0 = not true, 1 = somewhat true and 2 = certainly true). A cut off for ASD of > 18 has been suggested (Ehlers et al., 1999).

#### Data collection and data analysis

In Studies I–III, two experienced SLPs at the CNC collected the data for the children who had screened positive for ASD. The author scored and analysed the language tests from the 7.5-year assessment. The test results from the 3-year assessment were scored and analysed by the assessing the SLP or the child neuropsychologist who collected that data. The data compilation was carried out by the author. The author also collected the data for the children in the comparison group together with Master's students in their last year of the SLP programme, of whom most were supervised by the author. In Study IV, all data were collected and analysed by the author, and the data analysis included continuous discussions with co-authors. The interview texts were analysed and interpreted using a phenomenological hermeneutic method (Lindseth & Norberg, 2004). The interpretation included three distinct phases: naïve understanding, structural analysis and comprehensive understanding.

#### Statistical analysis

A variety of statistical methods were used in the different substudies, each chosen after considering the respective research question, group size and type and distribution of the variables included in the analyses. In Study I, group comparisons using parametric methods (ANCOVA and ANOVA) were used to compare reading profiles. In Study II non-parametric  $\chi^2$  –tests and binominal tests were used for group comparisons because of the categorical data and to examine performance above chance level, respectively. In Study III the non-parametric Kruskal-Wallis test was chosen for the group comparisons, in part since some of the included variables deviated from normality. The pairwise comparisons were done using the Mann-Whitney U-test. The correlations were calculated using Spearman's Rho correlation. In addition, a regression model was performed using one of the BST subscales (Sentence Length) as the as a dependent variable, since it was considered a good candidate after normality checks. The  $\alpha$  level was set to p < .05.

The IBM SPSS Statistic software version 25 was used for computation. In Study IV, the NVivo (NVivo, 2012) software package was used to organise and structure the interview data for analysis.

In Study III, both inter- and intrareliability of the BST ratings were calculated. The intra-class coefficient (ICC) was used as statistical method, adapted to the two-way mixed model (Fleiss, 1986). The author performed all the initial coding for the three BST scores from the ASD group. Eleven (24%) of the BST transcriptions were re-evaluated by a second independent coder (an experienced SLP). Then 14 (19%) of the transcripts from the comparison groups (LM and CAM combined) were re-evaluated (inter-rater reliability) by the author. Twelve (27%) of the transcripts in the ASD group were re-evaluated by the author, and the intra-rater reliability values were found to range from good to excellent. The reliability results were presented in Study III. Overall, the reliability of the data coding appeared to be sufficient. The reliability for the included test instruments was presented in Studies I and III

### Ethical considerations

The project received ethical approval from the regional ethical review board in Gothenburg, Sweden (case number 494-08 and 723-13). All included studies were carried out in accordance with the 1964 Helsinki declaration.

#### Information and consent

Several ethical considerations were made in the planning and execution of the present thesis project. Oral and written informed consent was provided by at least one of the parents/responsible caregivers of each participating child, both in the clinical group and in the comparison group. The participants could withdraw from the study whenever they wanted to without being subjected to any restrictions in forthcoming health care treatment. For instance, some children did not perform all tests, and in these cases it was important to be sensitive to what the child wanted in the particular situation.

All data were anonymised using individual identification numbers, such that the data could not be traced to any individuals without a code key. Thus, the children's identities were not available to the author during analyses/the project, and the code key was stored separately. In Study IV, details about the participants were anonymised in a way that made identification and recognition difficult.

### Results

For the purpose of this thesis, a total of 85 participants were recruited from the 2.5-year-old ASD screenings in Gothenburg, Sweden. However, due to either chronological age, the assessed abilities and/or the topic of the respective substudies, different numbers of participants were included in each substudy. The inclusion and exclusion criteria are described in each substudy. To give an overview of the participants included in Studies I–III, Figure 5 shows the total numbers for each substudy as well as the overlap. Although great care was taken to create a test battery that was suitable for as many participants as possible, due to the great heterogeneity in language skills (from non-verbal to above average) a relatively large number of children with ASD were not able to participate in the assessments and consequently not being included in the documented results.

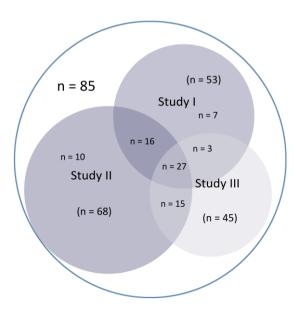


Figure 5. Number of participants who had screened positive for ASD included in each substudy

RESULTS 36

#### Study I

Current Profiles and Early Predictors of Reading Skills in School-Age Children with Autism Spectrum Disorders: A Longitudinal, Retrospective Population Study.

The specific research questions in Study I were:

- Which reading profiles can be identified in the sample?
- How are the reading profiles associated with concurrent measures of language, phonological processing, non-verbal cognitive ability and autistic severity?
- To what extent are the reading profiles associated with language, cognition, communication and social functioning, and autistic severity measures taken at age 3 years?

To investigate reading ability in the sample we split the sample into subgroups based on reading profiles, in line with previous research in the field. The subgrouping procedure was based on a cut-off at stanine score of  $\leq 2$  (which corresponds to the  $\sim 10^{th}$  percentile) on standardised assessments of single word reading/decoding and reading comprehension. The results showed that 25 (almost 50%) of the 53 included children were classified as what will be referred to as 'poor readers', meaning that they scored below the cut-off level on both measures (see Figure 6). One third (n = 20) were classified as 'skilled readers' since they performed above the cut-off on both measures, while approximately 19 % (n = 10) scored above the cut-off on word reading/decoding but below on the reading comprehension measure. The latter subgroup is referred to as the 'hyperlexic/poor comprehenders' group. No child showed a profile of poor word decoding and relatively better reading comprehension (sometimes seen in samples of dyslexic readers).

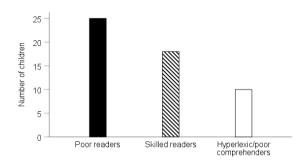


Figure 6. Number of individuals in each subgroup.

To explore the association between measures of structural language, phonological processing, non-verbal cognitive ability and autistic symptomatology at 8 years of age and reading ability profile, the subgroups were compared (using an ANCOVA for analysis with correction for age). The results showed that in terms of oral language, there were significant group differences, with post hoc comparisons showing that the 'skilled readers' performed significantly better than both the 'hyperlexic/poor comprehenders' and the 'poor readers'. Further, we examined phonology, which has been linked with word reading ability. Group differences were found also for phonological processing as per non-word repetition, with the post hoc comparison showing that skilled readers and hyperlexic/poor comprehenders did not differ from each other, while both of these groups performed better than the poor readers on this measure. The same pattern was seen for ASD symptoms, where the two groups ('skilled readers' and 'hyperlexic/poor comprehenders') did not differ but 'poor readers' presented with more symptoms according to their parents' ratings on ASSQ.

A unique feature of this study is that we are able to explore predictors of reading profiles in a longitudinal design by using the data from two time points, i.e. from age 3 and age 8. We examined subgroup differences in language comprehension and production at the 3-year assessment (using an ANOVA), and significant differences between groups were evident for language comprehension: the skilled readers performed better than both other groups. The groups did not differ when comparing the general developmental quotient or degree of autistic severity.

In sum, the results showed a clear association between language ability and literacy, and that especially reading comprehension and language comprehension are closely associated – an association seen already at age 3. Phonological skills at age 8 aligned more closely with single word reading/decoding ability.

#### Study II

Assessing False-Belief Understanding in Children with Autism Using a Computer Application: A Pilot Study

The specific research questions in study II were:

- Can children with and without ASD complete the FB task using a computer tablet?
- Do the children perform above chance level on the FB task in all three conditions: *narrative*, *silent* and *interference*?
- In each of the three conditions, does the performance differ between the children with and without ASD? Related to this, we also specifically

asked whether FB performance was verbally mediated, i.e. whether the performance was influenced by verbal support in the ASD group such that performance limitations were particularly prominent in the interference condition.

In order to investigate the influence of verbal support and structural language ability on FB performance in ASD, we i) manipulated the access to language support during the processing of the FB scenario in the app and ii) examined the performance of the ASD group in subgroups differentiated by structural language ability.

The manipulation of the app included a FB scenario presented in three auditory conditions: (1) a condition where a description of the content of the film was given (*narrative*), (2) a silent condition (*silent*) and (3) a verbal vocabulary interference condition (*interference*), i.e. the film contained random auditory interfering words intended to hinder the use of language mediation during the processing.

Of the 68 targeted children with ASD, a minority 16 (25%) did not manage to complete the full FB task. Thus, 52 children with ASD completed the task. These 52 children had a lower success rate than the 98 age-matched non-ASD peers for this task. The children with ASD did not perform above chance level (25%) in any of the conditions, while the comparison group had a success rate of around 50%. When comparing the performance of the groups in the three conditions, the ASD group performed significantly worse in two conditions, *narrative* and *silent*, but not in the *interference* condition, where there were no significant group differences; see Figure 7.

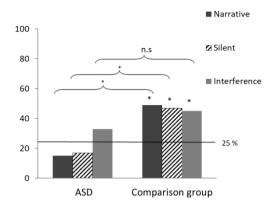


Figure 7. Success rates (percentage of children passing) for the FB task in the three conditions (narrative, silent and interference). \* result significantly

In order to explore to what extent language ability, and more specifically syntax, is linked with FB performance, complementary analyses were performed by selecting participants from the ASD group with at least an average language ability (above standard score 70 on TROG-2). The pattern was quite similar; they did not perform significantly above chance level for the narrative or the silent condition but interestingly, they exceeded chance level for the interference condition (see Figure 8). Yet again, no between-group difference could be seen in the interference condition but fell just shy of significance both the narrative and the silent conditions.

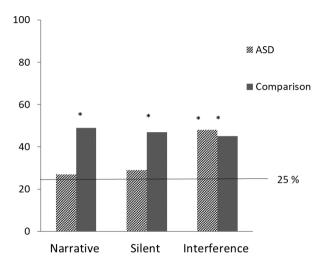


Figure 8. Success rates (percentage of children passing) for the FB task in the three conditions (narrative, silent, and interference). \* indicates result significantly above chance level, p<.05.

In sum, the results showed that the children with ASD performed poorer in all three conditions, in fact not even above chance level. The comparison group also performed somewhat worse than expected with respect to their age, yet clearly above chance level. Yet, the between-group comparisons revealed that the interference condition was the only condition where the ASD group's performance did not differ from that of the comparison group. Furthermore, when the performance of the children with ASD and average language skills was analysed separately,

they scored above chance level in one condition, the interference condition. Besides this result, which was contrary to our original hypothesis, no clear influence of language ability on FB understanding could be observed in the ASD group.

#### Study III

Narrative Skills in Primary School Children with Autism: Relation to Language and Nonverbal Event Seauencing.

The specific research questions in Study III were:

- Is there a difference in narrative ability between children with ASD and children without ASD matched on chronological age and between children matched on structural language ability?
- How is structural language ability, non-verbal cognitive ability, degree of autism symptomatology and/or nonverbal sequential reasoning related to narrative difficulties in children with ASD?

In order to examine how structural language ability assessed at the word and sentence level relates to narrative difficulties in ASD, we i) compare the narratives produced by the children with ASD with a comparison group matched on structural language ability (and another group matched on chronological age) and ii) perform a linear regression analysis in order to explore what variables influence narrative performance in the group of children with ASD.

The group matching included 45 children with ASD, 47 children without ASD matched on chronological age (CAM) and a group of 27 chronologically younger children (LM) without ASD who were matched according to raw scores for receptive grammatical language ability (TROG-2) (p=1.0) and 'Recalling Sentences' (CELF-4) (p=0.2). In Study III, the results showed that when comparing the three BST measures, i.e. Information, Sentence Length and Subordinate Clauses, the children with ASD performed significantly worse than the CAM-group on all three narrative subscores according to non-parametric Kruskal-Wallis tests (see Figure 9). Compared with the LM group, they performed worse on both Sentence Length and Subordinate Clauses, whereas there was no difference in Information subscores. In addition, the CAM and LM groups differed on all three scores, reflecting the expected finding that the older children (those in the CAM-group) scored higher than the younger children (those in the LM-group) on the narrative task.

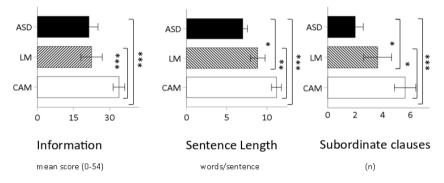


Figure 9. The three measures of oral story retelling ability assessed using the Bus Story Test (BST) for the three groups of children: ASD = children with autism (n = 45), CAM = chronological-age matched children (n = 47), and LM = Language matched children (n = 27). Error bars show the 95% confidence interval. \* p < .05, \*\* p < .01, \*\*\* p < .001

When trying to identify explanatory variables for narrative performance in ASD, linear regression analysis revealed that language ability at the sentence level (measured with Recalling Sentences) and nonverbal sequential reasoning explained unique variance in narrative ability.

In sum, the results showed that the children with ASD performed worse than agematched peers on the narrative task. Additionally, when they were compared with a younger group of children without ASD, matched for structural language (test scores at the word and sentence level), they still produced fewer subordinate clauses and used shorter sentences in their retold narratives. Finally, our results show that sentence recalling and nonverbal sequential reasoning explain unique variance in narrative performance among children with ASD.

#### Study IV

Negotiating Knowledge: Parents' Experience of the Neuropsychiatric Diagnostic Process for Children with Autism.

The specific aim of Study IV was:

- to gain an understanding of the parents' lived experiences of going through the neuropsychiatric diagnostic process

In this qualitative study, 11 parents were consecutively recruited and interviewed with the aim to explore their perspectives of having a child with suspected ASD

going through the neuropsychiatric diagnostic process. This is an important perspective in this study since the feasibility of early screening is often questioned (Siu et al., 2016), even though parents often recognise symptoms of deviant language and communication development early in development (Dahlgren & Gillberg, 1989).

Table 3. Themes and sub themes that emerged from Study IV

Negotiating Knowledge						
Seeking knowledge	Trusting and challenging experts	Empowered but alone				
Searching for information	Meeting the experts	Timing of resources				
Meeting the CHC	The assessment an unfamiliar situation	Expecting support				
Their way into the clinic	Being part of a large amount of logistics	Advocating for the child's needs				
Feeling anxious	Divergent emotional reactions	Handling the child's disability				
	Need for information	Dealing with transitions				
		Unequal resources				

The essential structure and the three main themes that emerged was 'negotiating knowledge': (1) 'seeking knowledge', (2) 'trusting and challenging experts' and (3) 'empowered but alone'; see Table 3. The parents expected intervention to start directly after diagnosis but felt they had to fight to obtain the resources their child needed. Each theme is presented below, along with quotes.

#### Seeking knowledge

The first theme concerns the time before assessment. The theme consisted of two subthemes, 'noting the child's disabilities' and 'feeling concerned'. The parents described that a common reason for their early concerns was that their child showed signs of deviant and delayed communication and language development.

'It was the communicative part /.../ she has always been late with her speech'

#### Trusting and challenging experts

The second theme that emerged from the data concerned the time at the clinic, i.e. the 1-2 months between the first appointment and the diagnosis. The parents described that they needed to trust and adjust to the professionals' way of responding to the child during assessment even if they did not always believe it was suitable for their child. Some parents said they had been seeking an explanation to their child's development, and that they felt relieved and that they had come to the right place at the CNC.

'I remember the moment we opened the door at CNC, it was like, just a big sun, and I felt like, wow, we have come to the right place.'

#### **Empowered but alone**

The third theme concerned the time from the diagnosis to the time they met me for the interview. The parents described the long wait for the intervention to begin as difficult. Some families waited 9 months for the intervention to start, and sometimes it started with the child going through a new assessment. Further, the parents described that they felt empowered but alone after the diagnosis, i.e. although they received useful and important information about their child, they reported a feeling of being left to manage the situation by themselves. The parents described that they received sufficient information about their child's way of functioning, but also that they felt left alone in the end of the process because the intervention was delayed.

'They identify something, and it's like, this very nice and important gift dropped in your lap, here you go, now go ahead and live your life'.

Handling the family's everyday living was described as very challenging and required daily work. The parents had to develop a structure for planning every detail of every day, i.e. a constant struggle for the child and the family.

'It is almost like playing real-life Tetris actually'.

In sum, the parents described key experiences of having a child go through an autism diagnostic process. Some suggestions were then implemented at the CNC in order to provide better care for new children who are referred due to suspected autism.

## Discussion

It has already been well established in the existing literature that structural language ability (at the levels of phonology, vocabulary and sentence) varies greatly among children with ASD (Egisti et al., 2011; Gernsbacher et al 2015). To what extent structural language abilities (at the word and sentence levels account for the communicative difficulties in ASD? In this thesis, I have approached the issue from several different methodological perspectives and by focusing on a number of key communicative skills that are known to have important impacts on general development and functioning in children. The main aim of the thesis was thus to investigate how structural language skills are associated with complex communicative functions – specifically, aspects of literacy, ToM and narrative ability in a sample of school-aged children who had screened positive for ASD and who had undergone in-depth neuropsychiatric and language diagnostic assessments. Considering the important roles of families in shaping children's language socialisation, a secondary aim was to explore the parental experiences of having a child go through the neuropsychiatric and language diagnostic process.

To summarise, structural language skills (at the word and sentence level) were shown to be associated both with reading profiles and narrative ability in children with ASD which is in line with previous research in the field. These findings underscore the need for a comprehensive assessment of structural language abilities in the work-up of young children with ASD, in order to support children and families. However, the current study results also provide evidence that structural language abilities alone cannot explain all aspects of communicative difficulties in ASD.

In Study I, the results showed that a large proportion of the children were found to have difficulties with reading ability, and the association with oral language ability was found to be strong, suggesting reading and language intervention for a substantial proportion of the included children (Arciuli & Bailey, 2019; Åsberg & Dahlgren Sandberg, 2010).

Study II results showed that the children with ASD performed worse on the ToM task in keeping with prior research on ToM and ASD. The role of language support was examined through subgroup analyses of those with stronger language skills and, uniquely, through a manipulation of verbal support during the ToM task. It was not possible to arrive at definitive conclusions regarding to what extent language is associated with ToM in ASD.

Study III, results showed that language ability at the sentence level was an important predictor of the ability to retell oral narratives. Importantly, however, language ability at the sentence level was not the only ability involved according to matched group comparisons and regression analysis; the latter kind of analysis revealed that nonverbal sequential reasoning also played an important role in narrative performance. This finding could have implications when planning interventions for children with ASD and narrative problems.

In Study IV, the findings suggested that families need more well-timed support and intervention in close connection with the child's diagnosis.

Future studies should focus on language ability and other possible predictors of communication development in children with ASD, and place more emphasis on the families' needs, by involving them when in developing better care.

# Communicative functions – the relation to language ability in ASD

Reading acquisition is a complex developmental process that - according to generally agreed perspectives in reading research can be conceptualized in terms of a dual component view, that comprises: i) word reading/decoding i.e. the process of transforming printed letters into speech sounds and words (Lundberg, 2002), and ii) reading comprehension, that according to a generally accepted view can be considered to be a product of word decoding skills and oral language/listening comprehension: the 'Simple view of reading' (Gough & Tunmer, 1986; Hoover & Gough, 1990).

Difficulties with single word reading/decoding have been shown to be associated with phonological deficits in general reading research (Høien, & Lundberg, 2000; Svensson & Jacobsson, 2006). Deficits in reading comprehension have been found to be associated with deficits both in decoding and/or oral language comprehension in non-ASD children (Hulme & Snowling, 2009).

In Study I, a subgrouping procedure was utilised to expand the understanding of the previously shown variability in reading skills in children with ASD (Åsberg et al., 2010; Brown et al., 2013; Nation et al., 2006; Norbury & Nation, 2011; White et al., 2006). The reading profiles identified in the sample were 'poor readers', 'skilled readers' and 'hyperlexic/poor comprehenders' (i.e. strong word decoding but poor reading comprehension) in line with a subgrouping procedure used in earlier research (Nation et al., 2006). In addition, even within individual children, the current study confirmed that some children with ASD show an uneven profile of strengths in word reading and word reading-related skills (phonology and pos-

sibly non-verbal ability) but difficulties with reading and language comprehension. Strong phonological processing (non-word repetition) was also associated with the reading profiles of 'skilled readers' and 'hyperlexic/poor comprehenders', suggesting that phonology is important for word reading performance, which insimilar to findings in earlier studies of children with and without ASD (Åsberg & Dahlgren Sandberg, 2012; Newman et al., 2007).

There have been previous studies that support the idea that poor reading comprehension in children with ASD may reflect underlying difficulties with social-communication (Åsberg et al., 2010; McIntyre et al. 2017; Ricketts et al., 2013; Westerveld et al., 2017). For example, having difficulties understanding social and communicative norms may hinder inference-making while reading and therefore affect reading comprehension negatively (Ricketts et al., 2013). This was considered to be a possible outcome in the current Study I as well, but the results did not convincingly support that idea since the 'skilled readers' and the 'hyperlexic/poor comprehenders' subgroups did not differ as regards autism severity. Rather, the results indicate that the 'simple view of reading' theory not fully account for the reading (comprehension) difficulties in these children with ASD, since children who struggled with reading comprehension displayed language comprehension difficulties irrespective of word decoding skills. The longitudinal analysis also showed that children with poor reading comprehension displayed oral language difficulties already at 3 years of age.

In Study II, our intent was to test the idea of ToM varying depending on the amount of verbal support given during the assessment. The task was presented in three conditions – narrative, silent and interference – where the narrative condition was hypothesised to provide verbal support in the same manner as the test is traditionally used, and this new interference condition was hypothesised to hinder access to language reasoning during ToM processing. As expected, the children with ASD performed poorly on the task (Baron Cohen et al., 1985; Happé, 1995). In fact, they did not perform significantly above chance level in any of the conditions while the children in the comparison (non-ASD) group did. Statistically significant group differences between the children with ASD and the comparison group were also confirmed with the ASD group showing worse results in narrative and silent condition while no difference was shown in the interference condition. Thus, the results confirmed a large literature pointing to ToM being impaired in ASD. When separating out children with ASD and an average structural language ability no clear differences were found in the narrative or silent conditions. This analysis was motivated by theoretical considerations and empirical data linking high language level to better performance on ToM tasks (Happé, 1995).

The inclusion of the interference condition was a novel feature of the study. Happé (1995) hypothesised that individuals with ASD who perform well on ToM tasks might solve them in an unusually conscious and logical manner, namely in 'a language mediated fashion' (Happé 1995, p.852). According to this hypothesis, an

individual with ASD with stronger language skills might rely on language-mediated reasoning during belief attribution. This proposal has rarley been tested directly, and in our study we used a manipulated ToM app in order to potentially shed light on this issue. However, we found that the children with ASD and an average structural language level perform above chance level *only* in the interference condition. This was not an expected result and should therefore be interpreted with caution in view of the limited sample size (Simmons, Nelson & Simonsohn, 2011). What is interesting, is that a few recent studies have shown increased alertness to social information following signals (Kleberg, Thorup & Falck-Ytter, 2016) and white noise (Söderlund, Sikström & Smart, 2007; Söderlund & Jobs, 2016) in studies of children with neurodevelopmental disorders. It is possible that the interference condition had such an 'alertness'-rising impact on the participants in Study II as well.

Also important to consider is that typically developing children have been found to pass the traditionally Sally-Anne test around the age of 4 years (Wellman, Cross & Watson, 2001). Our comparison group showed a success rate of around 49 %, whereas in other studies using traditional 'social' FB tests (Sally-Anne test), the success rate in comparison samples has been around 80 % (Baron-Cohen et al., 1985). In that sense, the performance of the non-ASD comparison group was lower than expected in our study that utilized a tablet-mediated presentation.

In Study III, the group comparisons showed that the children with ASD performed worse on two BST subscores than both of the matched comparison groups (cf., King et al., 2013) except for the Information subscore, where the children with ASD performed at the same level as the younger children matched on structural language ability. The latter results are in line with Diehl et al. (2006) where no differences were found between ASD and non-ASD children. Our results indicated that the difficulties with narrating seen in children with ASD did not only depend on language ability at the sentence level alone but also on other abilities, separate from difficulties involved with structural language ability.

To scrutinise this finding further, the next step of Study III was to investigate potential predictors of narrative ability within the group of children with ASD using a regression model. The results from the regression analysis showed that recalling sentences together with nonverbal sequential reasoning explained unique variance in the narratives given by children with ASD. This confirmed that structural language capacity assessed with tests of word and sentence skills cannot explain all narration difficulties in children with ASD, but that there is also a role of nonverbal sequencing as measured using the Picture Arrangement subtest (WISC III). The latter result is in line with some previous research (Åsberg Johnels et al., 2013).

The Picture Arrangement subtest has been suggested to index central coherence, i.e. the tendency to focus on context, coherence and global meaning rather than details when interpreting events and situations (Happé & Frith, 2006). The task is

performed non-verbally, which makes it easier to isolate any unique impact of sequential event reasoning from language capacity. Thus, the poor result on oral retelling for the children with ASD in my study could perhaps be explained in terms of weak central coherence (besides structural language).

To sum up, the association between the reading profiles and structural language ability confirm that reading comprehension ability in 8-year-olds with ASD is associated with oral language comprehension performance, and word decoding with phonological development. The skilled readers performed much better – and very close to normative levels – on tests of vocabulary, receptive grammar, and non-word repetition. In contrast to Studies I and III, in Study II it was difficult to draw any certain conclusions regarding the extent to which structural language is associated with FB performance, since in this study not even the children with ASD and an average structural language ability were able to perform above chance level. Therefore, the difficulties with ToM could rather be seen as distinct and separate from any difficulties in oral language level among children with ASD. In a similar vein, narrative performance in ASD might be closely associated with structural language skills at the word and sentence level, but this is not the only explanation.

#### Parent experiences

Speech and language development in children take place in the context of family and parents (Rowland, 2013). Hence, parents are often those who recognise their child's communication difficulties early on (Dahlgren & Gillberg, 1989). Little attention has been given to parents' views of early screening, but one frequently asked question in this context, is whether early screening may result in any harm for families. One secondary aim of this thesis therefore was to investigate the parent perspectives of having a child go through the neuropsychiatric and communication/language diagnostic process in order to increase the understanding of their lived experiences. I found that parents felt that they received valuable and sufficient information during and after the diagnostic process, but that they felt they needed to wait a long time before interventions started. Sometimes, they even had to go through the process of a new assessment of their child and themselves.

To return to the question of early screening potentially causing harm, there were indications in the interviews that parents gained increased knowledge about their child's needs, and therefore expected, immediate support and intervention. Even though knowledge and information were considered valuable to enable understanding and supporting their child better, many parents mentioned feelings of being "left-in-limbo" in this task. In fact, one direct implication of this study was that a parent educational programme was developed and implemented at the study clinic and is currently delivered to all parents of pre schoolchildren who receive an ASD diagnosis at the clinic.

#### Strengths & limitations

A strength of the current thesis was that the four included substudies used different research designs; longitudinal (Study I), experimental and cross-sectional (Study II), cross-sectional group comparisons and regression analysis (Study III), and qualitative (Study IV). Another major strength of the study was that the included participants with ASD and their families were recruited from the population-based AUDIE-cohort (Kantzer et al., 2013). All participants with ASD came from the same cohort, as did the parents participating in the interview study (Study IV).

Still, several caveats that can be used to guide future research should be acknowledged. Firstly, one limitation of the thesis was the relatively high attrition from the originally targeted group of children recruited from the CHC-screening. This could possibly be explained by the heavy burden experienced by the families, something that became explicit in Study IV. An additional and somewhat related caveat that is somewhat connected is the high attrition from the substudies as well. due the great heterogeneity in language ability (from non-verbal to above average) which prevented some children from completing the tests. A relatively large numbers of children with ASD did not manage to participate in the assessments and were consequently not included in the results from the different studies. In some children (for example the minimally verbal ones) with ASD, it can be challenging to assess and evaluate language ability, let alone more complex communicative abilities, and sometimes the approach of testing in such cases is even considered inappropriate (Brignell et al., 2018; Charman, 2004). This became obvious in my study, even though the sample was quite large to begin with. This could have been handled by using language tests designed for younger children/toddlers in the assessment of some subjects, in order for a larger proportion of participants to be able to provide language data. This would not guarantee an improvement, however, since many of those children would have difficulties no matter what testmaterial is used, and using different tests for different children would also raise challenges regarding how to compare and relate test scores in from group analyses. From such a perspective, the fact that this project, systematically used the same test materials for all children can even be considered a strength.

In contrast, with this line of discussion many children with ASD actually perform relatively better in a structural test situation than in a "social" "communicative" setting (Charman, 2004). We used standardized test instruments that are commonly used, mostly with Swedish norms. When interpreting the findings, there is always a possibility that our standardised test results might not be representative of a child's everyday communicative behaviours. In the future, I would like to also include a measure "social" and "communicative" level such as observing the child communication and language ability in another situation outside the clinic (Westman Andersson, 2013).

Another possible limitation of this study is the test-instrument (the BST) used to assess narrative ability in Study III. This test rely on a narrative retelling task in order to evaluate narrative performance; however, this is not the only possible method. For instance, Demir, Levine & Goldin-Meadow, (2010) utilized a cued narrative production task based on story stems when assessing narrative ability, in order to elicit more freely generated stories. The BST was chosen since it has been shown that retelling stories is suitable both for preschool children (Westerveld & Vidler, 2015) and for older children with cognitive disabilities, as they, on average, produce longer and grammatically more complex narratives in story retelling narratives than in self-generated stories, where floor effects are common (Boudreau, 2008; Merritt & Liles, 1989). The BST includes picture support, something that could be considered a strength since it provides visual support when the child tries to remember the story. On the other hand, this may also be considered a limitation since one of the research questions involved nonverbal sequential reasoning and perhaps the similarities between the tasks could have an effect on the results by strengthening this association.

An important direction for future research is to examine how the choice of material and elicitation technique affects narrative performance in ASD and whether the predictors of narrative performance differ as a function of assessment method. A similar argument can also be raised as regards reading comprehension assessments (Keenan, Betjeman & Olsson, 2008).

In Study IV, a phenomenological hermeneutic methodology was used, in accordance with Lindseth and Norberg (2004), and based on the philosophies developed by Ricoeur (1976) and Husserl (1962). Phenomenological methodology has a strong and complex philosophical underpinning (Mustakas, 1994). The method outlined by Lindseth and Norberg – the one used here – is a more structured procedure of analysing than a more traditional phenomenological methods and could therefore approach to be considered as more suitable method for an unexperienced researcher (Creswell & Poth, 2017). A strength of the phenomenological methodology approach is that it can offer a level of in-depth knowledge about the lived experience of respondents that quantitative methods alone might not allow. This suited the aim of my study.

In order to ensure credibility (Lincoln & Guba, 1985) throughout the research process certain strategies including investigator responsiveness (creativity, sensitivity, and insight regarding the analysis) were applied (Morse et al., 2002). I did my best to achieve being a careful and sensitive interviewer, probing and taking notes during and after the interviews and using a responsive approach (Kvale, 1997). Conducting interviews is complex and it is important to create a nice and comfortable environment and to make the respondent trust the interviewer. The interviewer should also ask the respondent control questions during the interview in order to make sure that the understanding of the narrative is correct (Norberg & Lindseth, 2004). Sensitivity during analysis was supported through continuous on-

going discussions between the co-authors and supervisors. This is believed to enhance the scientific rigour and richness of the research Transferability, (findings generalizable to another setting) is crucial, and can be achieved through providing adequate information and making the analytic process clear, so that the reader can estimate the possibility of transferring the findings into another situation (Lincoln & Guba, 1985). In phenomenology a heterogeneous group varies from three to 15 individuals (Creswell & Poth, 2017). In the current study, the data-collection continued until 'saturation' was considered to have been 'reached'.

## **Conclusions**

Based on the results of the substudies of this thesis it is concluded that aspects of structural language are important for aspects of literacy and narrative ability in children with ASD. However, the study results also provide evidence that structural language alone cannot explain all aspects of communicative difficulties in ASD considered in the thesis. Indeed, the four different substudies were designed so as to carefully and comprehensively include several different aspects discussed in previous research. Another conclusion is that families who had their preschool child go through an autism assessment increase their knowledge about their child's functioning, yet often felt left alone in their struggles. Summing up, the current thesis have contributed with increased theoretical and practical knowledge about important correlates of communicative, and family functioning in ASD.

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# Future perspectives

This study has shown that structural language ability plays an essential role in both literacy and narrative development in children with ASD. The clinical implication of this is that it is essential to provide an in-depth language assessment in order to assess structural language ability as well as different aspects of complex communicative functioning in children with ASD. It is still unclear what can be done to help these children develop their structural language and communication. An increasing number of intervention studies of children with DLD (without ASD) have shown promising results, in the sense that focused parent- and therapist-mediated interventions can improve structural language capacities (Ebbels, McCartney, Slonims, Dockrell & Norbury, 2017). However, we do not know to what extent ASD and autistic traits moderate child responsiveness to such training?

The findings also indicated that literacy, both in terms of word reading and reading comprehension, needs to be thoroughly examined given the very considerable variability within the ASD group. There were skilled readers and poor readers, but also an important minority of children that demonstrated good decoding but poor comprehension skills already evident during the first school years. These children are perhaps particularly important to be aware of in the clinics and in schools; as pointed out elsewhere there may otherwise be a risk of overestimating them, since they appear to already have learnt how to read (Åsberg Johnels & Miniscalco, 2014).

Given that such a large proportion of children with ASD have reading difficulties, it is important to ask what can be done to help them. The established association between reading skills and structural language ability, perhaps indicates that intervention targeting structural language in children could be generalised to improved reading capacity (Arciuli & Bailey, 2019). Moreover, compensatory assistive technology could, potentially, be useful to improve or compensate for poor reading skills (Fälth & Svensson, 2015), and is often recommended for poor readers with dyslexia (Nordström, Nilsson, Gustafson, & Svensson, 2018). At the same time, it is important to remember that merely providing auditory support might not necessarily be helpful since the children also showed poor listening comprehension. Perhaps, trying out a multimodal support strategy might be one way forward for helping children understand text (cf., Heimann, Nelson, Tjus, & Gillberg, 1995).

Another important finding in my study was that non-verbal sequential reasoning seemed to play a role in narrative performance in children with ASD. Poor performance on this task might be taken as a proxy for weak central coherence. It would

be of interest to further investigate the skills and capacities that underlie nonverbal event sequencing.

Finally, there appears to be a need to develop support to families of children screening positive for ASD. The findings indicate a need for well-timed support after diagnosis in general. One way of supporting affected families would be to improve the collaboration between different actors in the health care system. In planning future research, it would appear to be valuable to design research projects where parents' experiences and needs are taken into account in a formal manner.

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# Appendix

#### Supplementary material Study I

Group comparisons on baseline measures for assessments at age 3-years using *t*-tests and ANCOVA between the current study sample and the remainder of the AUDIE cohort

Mean (SD)			Test statistic	Group differ- ences
Current sample		Remainder of the AUDIE co-	t-value / F-	p-value
		hort		
	n=53	n=54		
Age (months)	36.70 (5.73)	33.91 (6.71)	-2.31	*
Developmental Quotient (Grif- fiths')	80.67 (18.23)	82.78 (18.37)	.56ª	.577
Language comprehension (RDLS)	17.17 (18.19)	13.35 (14.71)	-1.19ª	.236
ADOS (severity to-	5.29 (2.82)	5.39 (2.88)	18 <sup>a</sup>	.861
Vineland socialization	75.22 (10.94)	77.33 (9.50)	.30ª	.302
Vineland communi-	74.42 (14.48)	76.08 (12.78)	.61ª	.543

Note: <sup>a)</sup> Corrected for age (ANCOVA result). \* p < .05

APPENDIX 68

#### Supplementary data Study II

Complementary analyses in the comparison group

One way-ANOVA between-subjects analyses were conducted within the comparison group, to compare those who failed the FB task with those who succeeded the task in the three conditions separately, i.e., the narrative condition, the silent condition, and the interference condition. The results show that those who passed the FB task (in all three conditions) were significantly older and had higher syntactic language ability, measured by both TROG- 2 and the recalling sentences subtest (CELF-4), than those who failed the task.

	Narrative condition	Silent condition	Interference condition
Age (years;months)	F (1, 96) = 7.20 *	F (1, 96)=4.30 *	F (1, 96) = 6.38 *
TROG-2 (standard scores)	F(1, 96) = 11.79*	F(1, 96)=6.67 *	F(1, 96) = 6.77, *
TROG-2 (block score, max 20)	F(1, 96) = 18.25*	F(1, 96)=10.59 *	F(1, 96) = 12.39 *
Recalling Sentences (CELF-4) (raw scores, max 70)	F(1, 95) = 16.75*	F(1, 95)=6.77 *	F(1, 95) = 14.77 *
Recalling Sentences (CELF-4) (scaled scores, max 20)	F(1, 95) = 9.71*	F(1, 95) = 2.65	F(1, 95) = 9.61 *

<sup>\* =</sup> p < .05

APPENDIX 69