# INTRODUCTION

Asperger Syndrome is a lifelong disability that affects life in almost every possible aspect. Many parents experience a distinct feeling from an early stage that the child is somewhat "different", often without being able to pinpoint the difference, only knowing it is the case. When the children who were considered different are growing up, how do they perceive themselves? Are they able to relate to their specific qualities with pride or sadness? How do they look upon and handle their relations to others? An amount of literature has been written by people with AS and the picture of its impact on everyday life may vary. One can, however, presume that hardly anyone manage to grow up without experiencing at least some hardship connected to the special features of the diagnosis. Despite the fact that these features are known through, among others, the DSM-IV (1994) and the Gillberg and Gillberg criteria (1989), and that most professionals have at least basic knowledge of AS, there is still much left to explore in the field. Many characteristics can be puzzling and cause amazement and inclination for bullying. According to Gillberg (2002) AS has become one of the most important diagnoses in the psychiatric sphere though it is only during the past two or three decades the knowledge has reached broader groups of people.

## Asperger Syndrome and Autism Spectrum Disorder

Asperger Syndrome (AS) is a disorder within the autism spectrum (e.g. Gillberg, 2002; Peeters, 1998; Wing, 2005). Others are infantile (Kanner's) autism, High-Functioning Autism (HFA), and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). The diagnosis PDD-NOS is used when the full criteria for other diagnoses within the spectrum are not met. The disorder is considered to have relatively weak clinical consensus (Matson & Boisjoli, 2007). Occasionally Childhood Disintegrative Disorder (Heller syndrome) is mentioned as being a part of the spectrum (Gillberg, 2002). All of the conditions share some core features: impairment in reciprocal socialization and communication, and restricted and repetitive behaviours with circumscribed (and occasionally odd) interests (Howlin, Baron-Cohen & Hadwin, 1999). AS became a diagnosis of its own in the early eighties when Lorna Wing (1981) published an article where the term was coined. Originally it can be traced to the Austrian paediatrician Hans Asperger who described a group of boys in an article in 1944 and referred to their mannerisms as "autistic psychopathy". In most cases AS is congenital but can in rare cases develop after a brain injury early in life (Asperger, 1991; Gillberg, 2002). It is described as a neuropsychiatric developmental disorder,

> "a variation of brain development – in the sense that there are psychological, behavioural, emotional and cognitive characteristics that have a biological basis" (Gillberg, 2002, p. vii).

According to Wing (1996) a majority of children with Autism Spectrum Disorder (ASD) possess characteristics that can be seen in both Asperger's and Kanner's descriptions of their respective conditions. She refers to ASD as a continuum that comprises all levels from severely mentally and physically retarded individuals with little communicative and social ability to extremely intelligent individuals with subtle social deficits. It is not unusual for a person to meet criteria from both syndromes or to receive a diagnosis of autism in early childhood that in adolescence instead correspond to the criteria of AS. The diagnosis of AS is assumed to be preferred over (high-functioning) autism since it has a more optimistic "tone", especially for parents (Gillberg, 2002; Peeters, 1998; Wing, 1996). It should, however, not be perceived as a "light" version of autism. Peeters (1998) discussed the differences between diagnoses within the autism spectrum in the following way:

> "Asperger syndrome may be a better indication that the child is able to speak, has advanced cognitive abilities and can use its imagination and is more interested in people than the passive child with autism who is locked in himself. But from an educational point of view the child with Asperger is still autistic and have the same basic problems with imagination and fantasy, social interaction and communication even if his functions are on a higher level" (p. 122).

In the fifth version of the Diagnostic and Statistical Manual of Mental Disorders, the final and approved version is scheduled to May 2013 (DSM-V: The Future Manual, APA, 2011), AS, PDD-NOS, and also Childhood Disintegrative Disorder are proposed to be included in a single broad diagnosis under the term "autism spectrum disorder". Individuals within the spectrum should be differentiated by levels of severity. The authors of the coming version claim that the present distinctions between the subtypes of ASD are associated with level of intelligence and verbal skills rather than the core features (Anestis, 2009; APA, DSM-V, Autistic Disorder, 2011) and therefore belong under the same heading. Ongoing discussions on the internet show different opinions and that the issue has an impact on both parents and individuals with AS. A reason for keeping AS as a separate diagnosis is that it has with time become part of the a person's identity (e.g. being an "Aspie"), and cannot easily just be changed to autism (e.g. Grandin, cited in Wallis, 2009). Baron-Cohen (2009) concluded that since AS became official first in the DSM-IV (APA, 1994), there has been too limited time for researchers to discover a possible biological difference between AS and Kanner's autism. Some authors suggested instead a revised and more detailed version of AS in the DSM because of its clinical utility as a distinct condition (e.g. Ghaziuddin, 2010; Matson & Wilkins, 2008).

Opposed to this, Lord (cited in Wallis, 2009) stated that the main reasons for removing AS from the classification system are that the diagnosis is confusing and it has not been proved that there are consistent differences between AS and autism in its milder variant. An amount of studies have failed to show that the two diagnoses are distinct conditions (e.g. Bennett et al., 2008; Howlin, 2003; Kamp-Becker, Smidt, Ghahreman, Heinzel-Gutenbrunner, Becker & Remschmidt, 2010; Meyer & Minshew, 2002;

Rinehart, Tonge, Brereton & Bradshaw, 2010; Verté, Geurts, Roeyers, Oosterlaan & Sergeant, 2006) but instead could be seen on the continuum of ASD (Notherdaeme, Wriedt & Höhne, 2010) as was mentioned earlier (Wing, 1996). There has also been a notion that the DSM-IV diagnosis of AS is unlikely or even impossible and that those who has received the diagnosis in most cases actually meet the criteria for autistic disorder (Dickerson Mayes, Calhoun & Crites, 2001).

When the concept ASD is used in the present thesis it refers to all diagnoses within the spectrum. Occasionally the terms AS and ASD are used interchangeably due to the author's effort to follow the terminology of the original authors and researchers.

## *Prevalence*

In a study by Ehlers and Gillberg (1993) a screening of 1519 school children aged 7-16 showed a prevalence figure for AS of 0.71% (0.97% of all boys and 0.44% of all girls). All the suspected and possible cases were counted. When only counting the definite cases the prevalence appeared to be 0.36% and a male to female ratio of 4:1 (0.55% of all boys and 0.15% of all girls). Few epidemiological studies of AS have been conducted due to its late introduction as a separate diagnostic category in the DSM-IV (APA, 1994) and the International Classification of Diseases-10th revision (ICD-10, World Health Organization, 1992). A review by Saracino, Noseworthy, Steinman, Reisinger, and Fombonne (2010) showed a median rate of 0.11% (range: 0.003–0.48%) in 13 published studies comprising 6-427 children with a median age of 8.0 years. Fombonne (2011) suggested in the most recent source that was found, a mean figure of 0.06% or 6 individuals per 10 000. He also found fewer cases of AS than autism in the survey.

Several of the recent estimations comprised a wider range of diagnoses within the autism spectrum which makes it difficult to get a grip of the prevalence of the separate conditions. A study on ASD by Posserud, Lundervold, Lie and Gillberg (2010) screening a total population of 7-9-year olds revealed an estimated prevalence of 0.87%. Matson and Kozlowski (2011) compiled studies from countries in Europe, America and Asia during 1997-2010 and found diverse results. Those that measured autism, ASD or PDD showed rates at 0.04-1.1%, a study that measured ASD but not autism 0.77%, and PDD-NOS and/or autistic features 0.15-0.62%. A recent Asian study reported rates of autism and AS at 2.5%. The cited studies reported sample sizes from slightly less than seven hundred to over three hundred thousand children and adolescents 3-18 years of age. According to a number of researchers (e.g. Baron-Cohen, 2009; Saracino et al. 2010; Matson & Kozlowski, 2011) there has been an increase in the prevalence of ASD which among other things depend on more awareness of the conditions leading to improved detection and change of the diagnostic procedures. The substantial variability in the prevalence rates could, as one explanation, depend on methodological differences. Instruments and interpretation of non-response have been suggested to have impact on the result (Posserud et al., 2010). The male to female ratio showed to be 3.6:1 in a school-based population study

(Baron-Cohen et al., 2009). Females may, however, show a somewhat different profile of symptoms which can cause a tendency to underdiagnose girls (Steyaert & De La Marche, 2008).

### *Gender Issues*

The AS ratio of males in relation to females when it comes to referrals and diagnostic assessment is almost ten times higher for males. Even if girls exhibit the same traits and abilities as boys, their symptoms seem to be more subtle and less conspicuous. They appear to show aggression to a lesser extent and to have better social skills. Many girls observe people with social skills and imitate their behaviour which gives them a superficial knowledge that may prevent others from noticing their comprehensive problems in that particular field. Girls with AS sometimes take part in drama lessons and with help from an excellent memory they are able to build scripts of conversations and situations that can be of help in real life. Faherty (2006) referred to females with AS as “a minority within a minority”. Even if AS is the same disorder in girls as it is in boys they are likely to perceive other burdens. Girls are expected to show more empathy and to read others’ minds while they receive less support to understand their social difficulties (Faherty, 2006; Wagner, 2006). McLennan, Lord and Schopler (1993) found that in a study with participants between 6-36 years of age, an IQ above 60 and a diagnosis of autism, the males were rated to be more “severely autistic” than the females on measures of early social and communicative behaviours but not on any other measures. A study by Kalyva (2009) showed a high prevalence of eating disorders in girls with AS, in this case anorexia nervosa.

Two studies on toddlers with ASD (Carter, Black, Tewani, Connolly, Kadlec & Tager-Flusberg, 2007; Hartley & Sikora, 2009) showed that the girls were more able on visual reception, while the boys showed better skills on language and motor tasks and also accomplished higher social competence and communication ratings. The boys did also reveal more restricted, repetitive and stereotyped behaviour while the girls were found to possess more of sleep disturbances and anxious or depressive features. Kopp and Gillberg (1992) found that girls, 6-10 years of age, showed more of language and social imitation skills than boys which to some extent concealed the core symptoms.

### *Language and Speech*

Individuals with AS differ from those with Kanner’s autism primarily because of a more elaborated language ability, higher intellectual capacity, and less conspicuous overall behaviour (Wing, 1991). The differences between AS and HFA, however, are considered vague and there is a lack of an unambiguous diagnostic criteria as was mentioned earlier (Bennett et al., 2008; Manjiviona & Prior, 1995; Spek, Scholte, & Van Berckelaer-Onnes, 2010). The criteria for AS in DSM-IV (TR) (APA, 2000) say that “there is no clinically significant general delay in language” development. Attwood (2007) pointed out that this may sound as if there are no qualitative peculiarities at all in the language skills when instead different deviant language abilities are part of the core symptoms in AS. Wing (1996) also stressed that several adolescents with AS do have a delayed language and speech development of some kind. She stated that even if the children usually begin to speak at the same age as typically developing (TD) ones, the way they do it is often far from normal (Wing, 1981). The speech may be pedantic with certain phrases repeated over and over and new words are being invented; neologisms. Ghaziuddin and Gerstein (2000) found that pedantic speakers produced more utterances than those without pedantic characteristics and it was also suggested that it was somewhat connected to circumscribed interests. The often large amount of information and knowledge possessed by persons with AS and “shared” with others without regard to the interest of the listener, can give an impression of being pedantic.

Other language and speech features in AS are semantic-pragmatic deficits like difficulties with turn taking communication, keeping the conversation going, and meeting verbal approaches from others. Deviant prosody is a common feature (Gillberg, 2002) and communication aspects like use and understanding of facial expression and gestures are also often affected (Wing, 1981). It is often difficult for children and adolescents to make a consistent summary of a course of events and to cover the gist of a story. Thus, pragmatism, the social and practical use of language, is a primary problem area for individuals with AS (Tornmalm, 2007).

Adults with HFA, with an early language delay, and AS, with no known language delay, were compared in order to find if and how the developmental difference had affected current functioning in language comprehension and expression. The result did not differentiate between the groups. It indicated that the language abilities on the whole were poor and the assumption that language development in AS is considered normal could be questioned (Howlin, 2003).

### *Social Perception and Theory of Mind*

Social perception or Theory of mind (ToM) refers to a cognitive ability to understand other individuals as having intentions; to “read” and interpret their minds of theoretical concepts like beliefs, thoughts, emotions and desires (Peeters, 1998; Ylvisaker, Hibbard & Feeney, 2006). Individuals are also supposed to adjust their own behaviour based on this ability (Ylvisaker et al., 2006). It is well established that individuals with ASD, with high or low IQ, have extensive problems with mentalizing or “folk psychology” (e.g. Attwood, 2007; Castelli, Frith, Happé, & Frith, 2002; Gillberg, 2002; Howlin, Baron-Cohen, & Hadwin, 1999). It has also been referred to as “mindblindness” by Baron-Cohen (1995) and can be seen in ASD in various dimensions. He used the axiom “seeing leads to knowing” in order to explain how TD individuals learn and find out things and the difficulties individuals with ASD experience daily in this field. It seems they pass the “seeing” part but seldom reach the “knowing” part and therefore often are unable to find meaning in the actions of others.

Deficit in the social field could also be derived from a lack in the sense of relatedness with others (Hobson & Hobson, 2009).

A study comparing mind-reading in a group of adults with AS and a typically developing (TD) comparison group revealed a significant difference on a "naturalistic" task but not on two "static" ones (Ponnet, Roeyers, Buysse, De Clercq, & Van der Hayden, 2004). The first "static" task comprised stories with accompanying questions like "Was it true what X said?" and "Why did X say that?" and the second comprised photos of the eye region where the participants were told to make a choice between mental state terms. On the "naturalistic" task, the aim was to measure empathic accuracy as the participants watched videos in order to make inferences about the content of unexpressed thoughts and feelings. The result revealed both qualitative and quantitative differences between the groups. According to the authors this might be owing to the fact that individuals with AS focus on other behavioural cues than TD ones to infer that the behaviour and the thoughts and feelings of others interact (Ponnet et al., 2004). Facial cues are, for instance, used more often than others (e.g. tone of voice, gestures and body language). Despite the fact that individuals with AS have the ability to infer the affective condition of others on photos, there are obvious difficulties when several cues (body, voice, face and situation) appear simultaneously. When not being able to pay attention to all the present cues it could be complicated to understand a complexity like sarcasm (Koning & Magill-Evans, 2001) and failure to distinguish a joke from a lie or sarcasm from deception may cause confusing situations (Frith & Happé, 1999). In childhood this has also a crucial impact on pretend play (Baron-Cohen, Leslie, & Frith, 1985).

The social behaviour in AS can appear to be peculiar, not because of lack of interest to communicate, but because the ability to understand the rules connected to it is affected. Intuitive handling of social situations is seldom seen which has an impact on attracting new relations (Wing, 1981). In a review article Frith and Happé (1999) noted that even if the mentalizing abilities gets more elaborated in adolescence and later in AS it is still different from that TD individuals exhibit. The authors found that persons with AS require a substantially higher verbal ability to pass ToM tasks than TD persons do which means they will be older when they are able to pass the same ToM tests. They also concluded that the way young persons with AS approach social tasks could be described as to "resemble slow, conscious calculation" (p. 7). Castelli, Frith, Happé and Frith (2002) commented that

> "this finding suggests a physiological cause for the mentalizing dysfunction in autism; a bottleneck in the interaction between higher order and lower order perceptual processes" (p. 1839).

In an analysis of ten autobiographical accounts of social interaction experiences by adults with AS or HFA several themes and sub-themes emerged (Williams, 2004). The narratives described different aspects of the difficulties to relate to other people, how to manage, and when to fail (*Table 1*).

*Table 1* Themes and sub-themes in the social interaction field as narrated by adults with AS or HFA (Williams, 2004)

| Themes and *sub-themes* |
|---|
| Feelings of distance from other people |
| *Feeling like a detached scientist, recording observational data* |
| *Feeling like an alien, in need of an 'orientation manual'* |
| *Feeling like an onlooker to human interaction* |
| Inaccessibility of social and emotional cues for interaction |
| *The enigmatic nature of social interaction* |
| *Difficulty in picking up cues that are 'hidden' or inaccessible, both non-verbal and verbal social and affective information* |
| *Difficulty in picking up cues due to sensory problems* |
| *Slow or deviant development in the ability to 'read' emotional cues* |
| Coping strategies |
| *Studying other people's behaviour as a guide* |
| *Imposing rules in order to manage lack of social intuition* |
| *Using a 'visual library' to keep a 'record' of past social situations* |
| Limited success of coping strategies |
| *Failure of strategies in new or unexpected social situations* |
| *Difficulties in generalizing from one situation to another* |

### *Peer Relations and Friendship*

The influences of deficits in social perception are often huge. Social skills learned inherently by observation and imitation by TD individuals are usually learned in more systematic and intentional ways by individuals with ASD (Sinclair, cited in Sperry & Mesibov, 2005). This could be a reason for the social naïvity and lack of intuition that may cause awkward situations in work relations, and in developing and maintaining interpersonal relationships of different kinds (Sperry & Mesibov, 2005). Carrington, Templeton and Papinczak (2003) found that adolescents with AS had considerable problems in understanding the reciprocity of friendship and what constitutes friendship. The difference between what is and what is not a friend and how to perceive acquaintances in relation to friends were also found to be problematic. Many individuals with AS have had negative experiences with peers. Feelings of alienation in most social settings and, above all, in school, has been described in the literature and it seems that a considerable number of children and adolescents have lived through years of bullying (e.g. Attwood, 2007; Gerland, 1996; Jackson, 2002; Sainsbury, 2009)

### *Sense of Humour*

When examining adolescents on comprehension of cartoons and jokes it was found to be significantly poorer in an AS group than in a TD group. The surprise and coherence aspects of the humorous material were difficult for the adolescents to handle, one at a time was manageable but not both simultaneously (Emerich, Creaghead, Grether, Murray &Grasha, 2003). One could suspect that weak central coherence and deficits within the areas of EF and ToM, among other deficits, would have an impact on the perception of humorous material (Lyons & Fitzgerald, 2004). The latter authors also stressed that "the autistic type of humour" often means a verbal humour with primarily cognitive qualities that is based on linguistic and logical principles, has often been learned, and is not necessarily meant to be shared with others.

### *Executive functions*

Executive functions (EF) are connected to planning in order to attain a goal, to shift attention, to hold on to a strategy, to hold back or postpone the urge to gain immediate gratification, and the ability to perceive cause and effect. These abilities, and to act with reasonable swiftness are part of the core problems in individuals with AS (Bramham et al., 2009; Gillberg, 2002; Nydén, Gillberg, Hjelmquist & Heimann, 1999). Zandt, Prior, and Kyrios (2009) noted that children with ASD and obsessive compulsive disorder respectively, rated by their parents, revealed more of difficulties with executive functioning skills than TD children. When comparing the two groups the authors found that the ASD group showed impairment on tasks that requested multiple responses, and the OCD group revealed impaired inhibition ability. Impaired inhibitory control in ASD was found in a study by Mosconi et al. (2009) and it seemed to be associated with repetitive behaviour and symptoms of attention and hyperactivity (Verté, Geurts, Oosterlaan, & Sergeant, 2006). Verté et al. (2006) suggested that possible co-occurrence with (neuro)psychiatric conditions should be taken into account when using EF tasks because of the impact it might have on the result. Other difficulties connected to EF are prioritizing which task to concentrate on first, and time management. Inner speech in order to solve a problem has shown to be absent for many individuals with AS (Attwood, 2007). Nydén (2000) suggested that

> "global EFs could be thought of as various sets of combinations of specific information-processing components, such as Attention in combination with motor skills, Attention in combination with memory, Attention in combination with logical thinking, and so on. If the integration of these components is

> inappropriate, higher order cognition/conceptualisation will be impaired" (p. 45).

### *Attention Deficits*

It is not uncommon with attention and impulsivity symptoms in AS and some individuals also meet the criteria for ADHD as described in DSM-IV (TR) (APA, 2000), according to Gillberg (2002). A study that examined a great number of data from children who received community-based mental health services revealed that 43 percent of the children with ASD, but not autism, also met the criteria for ADHD (Bryson, Corrigan, McDonald & Holmes, 2008). In another study 75 percent showed symptoms of ADHD or deficits in attention, motor control, and perception (DAMP) which may point toward a considerable overlap between the disorders and AS (Sturm, Fernell, & Gillberg, 2004).

Attention is described as a complex process which can be divided into various functions. They comprise to *focus-execute* (to pay attention to environmental events and the execution of responses), to *sustain* (to keep up a focus on some aspect of the environment), to *shift* (to change focus from one aspect to another in the environment), and to *encode* attention (to be able to use working memory to remember what was attended to) (Mirsky, Anthony, Duncan, Ahearn & Kellam, 1991; Attwood, 2007). Studies have shown that there may be difficulties within all of these functions in persons with AS (e.g. Attwood, 2007) but it has also been found that attentional set shifting can be within the normal range (Nydén, Gillberg, Hjelmquist & Heiman, 1999; Rinehart, Bradshaw, Moss, Brereton & Tonge, 2001), and also, according to a review by Sanders, Johnson, Garavan, Gill, and Gallagher (2008), sustained attention ability. The findings within the field are contradictory and may depend on how the different researchers conduct the tests and also make use of contextual information (Ames & Fletcher-Watson, 2010).

Since ADHD is a frequent co-existing disorder it is, or should be, considered when evaluating children with AS according to Gillberg (2002). ADHD is divided into three subtypes: the hyperactive-impulsive, the inattentive, and the combined type (DSM-IV, APA, 2000). Children with AS may become overactive, impulsive and inattentive in social situations they find confusing and stressful but also in other situations that are not at all connected to stress, at least not in the typical population. Attention difficulties can also be seen when flexibility is required, like turn taking and listening to others (Frazier et al., 2001; Leventhal-Belfer& Coe, 2004; Lee & Ousley, 2006). It frequently happens that a child or adolescent appears to pay appropriate attention to a specific matter but fail to attend to what is of relevance (Attwood, 2007).

### *Sensory Perception*

Sensory sensitivity is more common in Kanner's autism than in AS but it seems to be present on all levels of the spectrum (e.g. Gerland, 1996; Holliday Willey, 2003; Jackson, 2002). It exists in connection to sounds but also to light intensity, tactile experiences, and smell, taste and texture of food. Pain can cause under- and over-reactions and the perceptions of one's own body may be unusual in balance and movement abilities, and in body orientation. The sensory system can vary in an individual and oscillate between hypo- and hypersensitivity. Complex sensory stimuli are often difficult to coordinate. Situations, for example in school, can be perceived as painful "sensory overloads" for young individuals with AS, but entirely normal and enjoyable for TD peers. Problems with sensory sensitivity can, in some cases, be the primary problem for adults with AS (Attwood, 2007; Sainsbury, 2009). It has been suggested that the abnormal sensory processing in ASD is global and that dysfunction in one modality does not stand independent of dysfunctions in others. Children, but not adolescents and adults, revealed a significant correlation between abnormal sensory processing and the severity score in autism in a study by Kern et al. (2007). Hochhauser and Engel-Yeger (2010) found that atypical sensory processing patterns were correlated with lower participation in leisure activities, especially with peers. Attention and sensory processing may be related, according to some authors (e.g. Liss, Saulnier, Fein, & Kinsbourne, 2006; Crane, Goddard, & Pring, 2009). It has been argued that a high non-verbal IQ score might be a protective factor against sensory processing deviances because the more limited attentional resources in a person with low non-verbal IQ would be used up at an earlier point (Crane et al., 2009).

### *Repetitive and Ritualistic Behaviour and Obsessive-Compulsive Features*

Rigidity, repetitive behaviour, pedantry, dependence on routines, and intensive interests, seldom more than one at a time, and isolated from adjacent topics, are parts of the core symptoms in ASD (Gillberg, 1997; 2002). Repetitive behaviour has been described by Turner (1997) as

> "un umbrella term which encompasses a wide range of behaviours including stereotyped movements, marked distress in response to changes in small details of the environment, an insistence in following routines in precise detail, and preoccupation with narrow, circumscribed interests" (p. 58).

Three characteristics are required for the definition of repetitive behaviour. First; a high frequency of repetition, second; identical performance every time, and third; that the activity is odd or inappropriate in the presence of others (Turner, 1997). Repetitive behaviour can be categorized as lower-level behaviours that comprise repetition of movement (e.g. stereotyped movements, repetitive manipulation of objects, and tics) and higher-level behaviours (e.g. insistence on sameness, repetitive language, and circumscribed interests) (Turner, 1997; 1999).

Rituals and repetitive behaviour are common parts of typical as well as atypical development. A community study by Leekam et al. (2007) showed that TD 2-year-olds were involved in ritualistic activity within four different areas: unusual sensory interests, repetitive motor movements, rigidity and adherence to routine, and preoccupations with restricted patterns of interest. Other authors have found intense interests that could be considered extreme in children from around 12 months of age (e.g. DeLoache, Macari, & Simcock, 2007). Evans et al. (1997) noticed that 2-4 year olds acted out a more compulsive behaviour than both younger and older children. In children, 1-4 years of age, it seems that repetitive behaviour might be connected to fearfulness in general and particularly fears of strangers. In older children, up to 7 years of age, it was more related to obsessive-compulsive characteristics (Evans, Grey, & Leckman, 1999). Zohar and Felz (2001) raised the question whether ritualistic behaviour during the preschool years runs the risk of developing psychiatric disorders like obsessive-compulsive or anxiety disorders or if it would be seen as a transitional feature that is likely to disappear.

Other features of the typical development are superstitions (e.g. breaking a mirror) (Bolton, Dearsley, Madronal-Luque, & Baron-Cohen, 2002) and magical thinking (e.g. it is raining because the sky is sad) (Evans et al., 1999). It has been shown that the latter is somewhat related to obsessive-compulsive thoughts and behaviours (Bolton et al.). Play and imaginative activities have been found to be associated with repetitive behaviour in children with ASD which indicates that children with few obsessive-compulsive features are more prone to engage in play activities than those who frequently engage in such behaviours (Honey, Leekam, Turner, &McConachie, 2007). A ritualistic behaviour may sometimes depend on an inability to create internal ideas and solutions. It may make a person do the same thing over and over again because s/he in unable to figure out a more appropriate way of handling situations (Gerland, cited in Bejerot, 2002).

Persons with ASD may continue childhood repetitive activity into adolescence and adulthood and this can develop into similar patterns that are seen in OCD (Wing, 1996). Making double diagnoses have been discouraged in the DSM (APA, 2000) and the ICD (WHO, 1993) manuals because a diagnosis within the field of autism is severe enough to “stand on its own”, but in some cases it may be difficult to separate the two disorders. When obsessions and compulsions are severely disabling, a co-occurring diagnosis could be useful (Gillberg, 2002). Russel, Mataix-Cols, Anson, & Murphy (2005) found that around 25 percent of adults with AS also fulfilled the criteria for co-occurring OCD. It is also common with co-occurrence within the neuropsychiatric field in children and adolescents with a primary diagnosis of OCD (Ivarsson, Melin, & Wallin, 2008). A study by Zandt, Prior and Kyrios (2007) indicated that a group of children and adolescents with HFA were engaged in similar amounts of “sameness” behaviours and repetitive movements as a group of children with OCD. The compulsions in the HFA group differed from those in the OCD group in being less “sophisticated”. The sameness behaviour in the OCD group turned out to be more common among younger participants, whereas older ones reported more obsessions.

Bejerot (2007) suggested that persons with OCD could be found on a continuum, with almost typical personality on one side and a severely autistic personality on the other. It has been argued that a co-occurring diagnosis of OCD might be complicated to make since there is no formal consensus of what could be the expected level of repetitive behaviour and rituals in AS (Zandt, Prior, & Kyrios, 2007), so this must be a subjective interpretation made by the clinician (Attwood, 2007). The criteria in DSM-IV (APA, 2000) that the obsessions and compulsions in OCD should be perceived as distressing might also be problematic to evaluate clinically in children and adolescents with ASD (Attwood, 2007). However, some studies have found that those features were experienced negatively and had an impact on the young persons' lives because of the distress they caused for both the youths and their parents (Mack, Fullana, Russel, Mataix-Cols, Nakatani, &Heyman, 2010; Russel et al., 2005; South, Ozonoff and McMahon, 2005).

### *Intense and Special Interests*

Individuals with AS often possess a strong fascination for certain topics and the interests that engage them can be extremely circumscribed (Gillberg, 2002). Wing (1996) pointed out that it may be difficult to know what will be an intense interest that lasts for a while or what will be compulsive enough to become a co-existing disorder of OCD. The interests are often advanced in its character, like memorizing hard facts and making complicated abstract analyses. Instead of collecting objects it is common with information collecting (Howlin, 2004). Adults in particular can at first be impressed by the amount of knowledge that is more or less forced upon them but soon it becomes tiring. Peers often perceive children and adolescents with AS as "weird" and the intensity in a special topic is seldom positive for social interaction with others (Gillberg, 1997). The excitement connected to the special interest can cause outbursts of anger when being interrupted (Barron & Barron, 1992; Jackson, 2002). Examples of interest can be the occurrence of different historical events, bus routes, sports results (Tantam, 1991), and computers (Jackson, 2002). The fact that individuals with AS who are interested in chess or computers never seem to discuss the topics with others and hardly ever join clubs or societies in order to meet people who share the special interest, is regarded as a deviance (Tantam, 1991), not necessarily the interest itself or the intensity with which it is performed. It has been suggested that the difference between OCD and the special interests in AS is that children and adolescents with AS tend to handle a shift of activities easier than children with OCD when presented with an attractive alternative (Leventhal-Belfer & Coe, 2004).

When Zohar and Felz (2001) explored ritualistic behaviour in TD young children they suggested that it could be seen as manifestations of fearfulness and expose negative emotions. The rituals could be an attempt to balance the fears and worries that often are present during the early years. According to Attwood (2007) excessive compulsions and rituals or intense interests in AS could be a sign of a high anxiety level. It seems probable that by repeating certain activities that are well known, a feeling of being in control may arise. The environment may now and then be perceived as difficult to understand for individuals with ASD and also for TD young children and that could be one reason for excessive rituals and routines.

### *Anxiety, Stress and Depression*

Mood disorders are thought to be overrepresented in AS (Russel & Sofronoff, 2005; Tantam, 2000). Several studies have reported depression in children, adolescents and adults (Balfe & Tantam, 2010; Cederlund, Hagberg, &Gillberg, 2009; Kim et al., 2000; Stewart, Barnard, Pearson, Hasan, & O'Brien, 2006) and it is also common that a considerable part of the participants in the studies are on medication (Barnhill & Smith Myles, 2001; Cederlund et al., 2009). Anxiety has also been more frequently reported in AS than in the TD population and the conditions have, as a consequence, been found to cause aggressive behaviour and impaired relations to peers, parents and teachers (Kim, Szatmari, Bryson, Streiner & Wilson, 2000). Studies have also shown that children and adolescents with AS or HFA may possess more overall anxiety than typically developing peers and that adolescents in some cases might suffer from an equal amount of anxiety as clinically anxious adolescents (Bellini, 2004; Farrugia & Hudson, 2006; Gillott, Furniss, & Walter, 2001; Russel & Sofronoff, 2005; Tonge, Brereton, Gray, & Einfeld, 1999). It may be complicated to discover depressive symptoms in AS since the facial expression and the tone of voice in many cases is rather expressionless regardless of the psychological condition (Gillberg, 1997). However, decreasing adaptive functioning, excessive social withdrawal and self-neglect may be signs of incipient depression (Stewart et al. 2006). Young persons with AS and HFA and high intellectual capacity have been found to perceive themselves as less socially competent than TD comparisons and have also, as a possible consequence, revealed higher levels of depressive symptoms (Vickerstaff, Heriot, Wong, & Dossetor, 2007)

Poor stress management is common in children with ASD. This may deteriorate during adolescence when the awareness about the impact of the diagnosis increases (White, Oswald, Ollendick & Scahill, 2009). According to Tantam (2000) there could be stressful situations for some individuals if and when their social adjustment abilities improve and they become more aware of other people and the feelings they may possess. The private world of special interests in order to cope with stress may be more difficult to withdraw into than before and the experienced vulnerability may be painful. Intense interests can be experienced as a retreat when this occurs and therefore become more intense than usual (Attwood, 2007; Tantam, 2000).

Even if stereotyped behaviours in most cases are less conspicuous as persons with AS grow older it happens that those behaviours become obvious in situations of distress or anxiety, and also boredom. It may be difficult to discern anxiety symptoms from an increase in AS symptom severity and it is of occurrence that anxiety may *result* from the intense interests or rituals. Fears and fascination seem to be closely linked together (Howlin, 2004). Some children and adolescents with AS appear to suffer from generalized anxiety disorder (GAD) that might be due to constant lack of intuition in, e.g. social situations (Tantam, 2000). Attwood (2007) suggested that persistent anxiety in AS could be an innate feature of a reaction to constant stress from coping with everyday life. Because of perceived unpredictability even small changes may cause anxiety and extreme actions in order to avoid additional situations of the same kind. Anxiety that lasts for a long time may lead to depression and the person may be at risk for substance misuse (Tantam, 2000) and suicidal thoughts or attempts (Balfe & Tantam, 2010).

### *Motor Ability*

Motor clumsiness is one of the criteria in the Gillberg and Gillberg diagnostic criteria (1989) and can in some cases cause problems in gross as well as in fine motor activities. Inability to coordinate and integrate gaze and movements makes it difficult to behave in socially acceptable ways in many situations. Demands from others to look them in the eye, to possess a proper posture and listen attentively at the same time may be more than a person with AS can manage (Tantam, 1998). Thus, individuals with motor clumsiness often experience social impairment as a result of the disorder (Miyahara & Piek, 2006). A study by Poulsen, Ziviani and Cuskelly (2008) showed that boys with developmental coordination disorder (DCD) were at risk for limited participation in physical activities with peers. The boys, 10-13 years of age, had lower mean scores on physical ability, physical appearance, peer and parent relations but also on measures regarding self-perception in general. Poor motor skills causing weak performance in physical education could increase the risk of being bullied (Bejerot & Humble, 2007). Consequences of this could be a more sedentary life (Poulsen et al., 2008) and adopting more of passive and avoidant strategies than typically developing children (Watson & Knott, 2006). A meta-analysis by Miyahara and Piek (2006) on physical disability showed that children and adolescents with minor disabilities (e.g. clumsiness or DCD) perceived themselves as less competent in physical performance and also in social life than peers with major physical disabilities (e.g. cerebral palsy). This might depend on how the person is treated by peers, parents and teachers; a young person with a visible disability probably receives more empathy and consideration than one with a disability that is not visible or understood by others. It often happens that the child with a minor disability has not received a proper diagnosis which makes identification with both the typically developing peers and those with some kind of disability difficult (Miyahara & Piek, 2006). In a study by Kopp, Beckung and Gillberg (2010) it was found that a sample of girls with ASD and/or ADHD also received a diagnosis of DCD in 25% of the cases.

### *Sleep Disturbances*

Problems with sleep onset and maintenance have been reported and do not seem to be related to age, IQ, gender or neuropsychological functioning. Negative attitudes toward sleeping, sleeping fears and drowsiness during daytime have showed to be more frequent among children and adolescents with AS than among typically developing (TD) individuals. (Dickerson Mayes & Calhoun, 2004; Paavonen, Vehkalahti, Vanhala, von Wendt, Nieminen-von Wendt &Aronen, 2007). Sleep disturbances have also been reported in adolescents and young adults with AS and the most frequent problems were found to be short total sleep time and long sleep onset time (Oyane & Bjorvatn, 2005).

### *Strengths*

Not much is written by researchers about the strengths and advantages with AS. In most cases this is only mentioned incidentally. Gerland (1997) stressed that special interests are worth emphasizing because it often leads to extraordinary skills and knowledge about the actual subject of interest. Other characteristics can be that the individuals are careful and eager to carry out their duties, e.g. finishing tasks. Rote memory and photographic memory seem to be strong abilities for about a third of the individuals (Gillberg, 2002) and to have a good sense of direction has also been noted. The intelligence quotient can in some cases be higher in an AS population than in the general population (Gillberg, 1997).

## Early Symptoms in Asperger Syndrome

### *Early Signs of ASD*

It is considered difficult to find reliable signs of AS during the first 2-3 years of life even though ASDs of all kinds are likely to be present at birth (Gillberg, 2002; Howlin & Asgharian, 1999; McConachie, Le Couteur, & Honey, 2005; Turner, Stone, Pozdol, & Coonrod, 2006). The specific features that often become obvious during the school years; language and speech peculiarities and communication deviances, are in many cases too vague to work as a safe base for an early diagnosis (Howlin & Asgharian, 1999; Gillberg, 2002). McConachie et al., (2005) found that patterns of repetitive and stereotyped behaviours among the more able children were common reasons for seeking professional help. The authors stressed that attention should be paid to unusual behaviours and also general behaviour problems like poor sleep and over-activity, especially if language problems (other than delay), social or play difficulties also are present.

Several studies have shown that infants with ASD have caused alarm for their parents during the first year (e.g. Werner, Dawson, Osterling, & Dinno, 2000; Maestro et al., 2004) and that they could be differentiated from both infants with mental retardation and those with typical development (Osterling, Dawson & Munson, 2002). As Wing (1996) pointed out, it may vary how the characteristics of ASD have manifested itself in different children and that it is not always easy to establish if a child has autism or AS. It is also often difficult to decide whether a functional scarcity is a deficit or a delay (Sigman, Dijamco, Gratier & Rozga, 2004). Parents have reported concern about their children's behaviour around 18 months for those later diagnosed with autism (e.g. Howlin & Asgharian, 1999) and during the third year for children later diagnosed with AS but also concern from some parents around their child's second birthday (Gilchrist et al., 2001; Howlin & Asgharian, 1999). Parents can in many cases retrospectively describe patterns of behaviour that were present during the first years of life.

Young, Brewer and Pattison (2003) pointed out that there is a difference between the core symptoms of ASD where the behaviour could be linked to the underlying neurological deficit and secondary manifestations that might be caused by coexisting disorders like intellectual disability. The authors found that concerns from parents during infancy comprised difficulties related to social awareness and understanding, lack of shared enjoyment, poor eye contact, no or little playing with other children, deviant gross motor development, language and communication problems. Social and communication problems were reported as separate entities and the communication problems were not noticed until the language development turned out to be abnormal. Despite early concern there was a delay on average of a little less than three years before a diagnosis was received (Young et al., 2003). There are some characteristics that are likely to fail when testing toddlers with ASD: proto-declarative pointing (pointing in order to direct others attention to objects or actions), gaze-monitoring (to look in the same direction on another person's request) and pretend play (Baron-Cohen, Cox, Baird, Swettenham, Nightingale, Morgan et al., 1996). Filipek et al. (2000) suggested some additional criteria that also should be taken seriously and lead to evaluation: a) no babbling, and no gestures at all by the end of the first year, b) no single words by 16 months, c) no "own" (not echolalic) two-word phrases by the end of the second year, and d) loss of language and social skills at any age.

### *The Benefits of an Early Diagnosis*

In the Howlin and Asgharian (1999) study the average age of receiving an AS diagnosis turned out to be 11 years and no child was diagnosed before the age of 3. There was a mean time gap of over 8.5 years from when parental concern arose until a proper diagnosis was made. Instead vague diagnoses like "autism spectrum disorder" or "autistic tendencies" were given significantly earlier than AS. Even if AS and HFA are considered to be less severe variants of autism a child with these disorders has basically the same kind of problems as one with a more pervasive disability and a diagnosis of Kanner's autism, even if the behaviour is less noticeable (Wing, 1996). This does not make it less important to recognize the impact of the disorder on everyday life. An early identification and intervention improves the prognosis for the children (Brian et al., 2008; VanBergeijk, Klin & Volkmar, 2008) and decreases the risk for negative behaviours to be chronic and increase in intensity (Matson, Boisjoli, Rojahn & Hess, 2009). Structure and well planned education is important for academic success and self-worth and may be hard to achieve without the support of a diagnosis (Perry, 2004).

Some researchers (e.g. Turner & Stone, 2007; Wetherby, Brosnan-Maddox, Peace & Newton, 2008) suggested that a reason for not diagnosing early may be difficulties in identifying developmental disorders in infants and toddlers. Atypical development in motor activities, self-help and adaptive skills as described in DSM-IV (TR) (APA, 2000) may be difficult to pinpoint and there is also the variety in typical development to consider (McConachie et al., 2005). Another reason could be the limited research on parental concern during the first 24 months in prospective studies (Wetherby et al., 2008). A retrospective study by Chawarska et al. (2007) revealed that one third of parents of children with ASD had reported developmental problems during the first year, half of them during the first 18 months and 80 percent during the first 24 months. These results were consistent with a prospective study by Wetherby et al. (2008). There seem to be a reasonable stability in the ASD diagnoses made around the age of 2 (Kleinman et al, 2008; Moore & Goodson, 2003; Stone et al., 1999).

A common way to evaluate behavioural development in young children is by parental questionnaires, retrospective or prospective (e.g. Dahlgren &Gillberg, 1989; Lord, Rutter, DiLavore & Risi, 2000; Rutter, Le Couteur & Lord, 2003; Scott, Baron-Cohen, Bolton & Brayne, 2002). Another source is home videotapes (e.g .Eriksson & de Chateau, 1992; Osterling et al., 2002; Werner et al., 2000). Few screening instruments are suitable for infants but one that has been suggested is The Infant/Toddler checklist from the Communication and Symbolic Behavior Scales Developmental Profile (Wetherby & Prizant referred to in Plauché Johnson and Myers, 2007) which is considered suitable from 6 months of age.

## Self-perception and Self-understanding

### *The Development of Self*

The development of self and one’s identity begins at birth. When infants are around eight months old they discover that there are other “selves” beside their own. This makes it possible to begin to “read” and interpret mental conditions in others. Around sixteen months a more subjective view of self and others is developing. There is a sense of both “me” and “the other” as having personal knowledge of the world (Stern, 1985). One example of this is when the infant can use a mirror to locate a spot of rouge on her/his own nose (Butterworth, 1992). When the infant can verbalize her- or him-self and the environment and can share it with others abilities like self-reflectivity and being able to use communicative speech have developed (Stern, 1985).

Bonding is also a part of the development of a self. The way an infant has been treated by the caregivers creates internal working models that indicate “the value” the child gives itself.  It is primarily situations of specific need, e.g. when the child is sad or upset, that are crucial for the development of internal working models (Broberg, Granqvist, Ivarsson & Risholm Mothander, 2008). At the end of the first year most babies cry in protest against being left alone or with someone they do not know well. This, according to Bowlby (1996), has been seen as evidence for a growing ability to create a working model of the caregiver in order to compare her/him with other people when s/he is not near and to recognize her/him when s/he returns. A secure bonding means that the child feels certain of the parents' support and comfort while an unsecure bonding makes the child afraid of being abandoned and it becomes hesitant to explore the world.

Identifying with other people's attitudes has important implications for the development of the self. The social-relational dimension of the self can be seen in qualities, levels and degrees of a child's self-perception (Hobson, Chidambi, Lee, & Meyes, 2006). The qualitative view comprises the content of the individual's perceptual ability as well as how it is being handled. The authors illustrated this with a child who is caring about someone as a person is also caring about the caring as part of the self-attribution. Levels of perceptual ability can range from implicit or pre-conscious to cognitively advanced activity of reflective understanding of self. Finally, the degree of self-perception has to do with how big a part of the individual perceptual ability that is active at a certain time. People are showing more sensitivity and reflective activity on some occasions than on others (Hobson et al., 2006).

The episodes of interaction with various persons in a life perspective are all parts of a general model of self with others. The early models of mum and dad may differ but eventually there will be consistent working models of the parents. From these experiences more general models of self and others will be formed. Bonding relations to love partners and close friends are influenced by the general models of self and self-with-others and the episodes of interaction that originate from relations that take place later in life are also affecting the general models. Thus, the internal working models are continuously being updated (Broberg et al. 2008). This is also confirmed by Reisberg (1997) who claimed that the self-perceptions is more than anything formed out of our own episodic knowledge and Guardo and Bohan (1971) who considered perception of self a quality that gets revised and refined in a lifelong perspective. According to Ouvinen-Birgersson, (1999) self-worth seems to be stable over time. High correlations on test-retest have showed reliable results in that respect for one and two years intervals.

### *The Damon and Hart model of Self-understanding*

To Damon and Hart (1988) thoughts and attitudes about oneself are the foundation of the conceptual system of self-understanding. According to them, the most pervasive changes in self-understanding during childhood and adolescence are: a) an early awareness of self influenced on one's own activity and eventualities that came from the activity, b) an early awareness of physical categories of self like gender and body size, c) an age-related shift from defining and describing oneself by external characteristics (physical, material and active categories) to internal qualities (psychological and spiritual or existential), d) an age-related tendency to integrate the diverse aspects of self into what appears to be a coherent system.

The self-understanding goes beyond the definition of the self here and now to considerations and thoughts of past and future life conditions. Distinguishing oneself from others is an essential part of self-understanding and this also includes self-interests, how they overlap and differ from others. According to the authors, self-understanding means that the self has both an objective and a subjective side.

### *Self-perception and Asperger Syndrome*

A child who was born with a disability does not look upon her- or himself as an aberration until someone tells her or him so. The crucial point is how other people react and treat her/him. In most cases the child eventually understands that s/he is different from others. A disability that is more or less invisible may cause expectations from the environment of denial or at least of concealment as much as possible. If and when this is not possible anymore the child becomes an outsider who belongs to a special kind of people. When people with disabilities are placed in another category than people without this often changes their self-perception and self-worth; they no longer feel able or appreciated. Low self-worth or depression may be the consequence of negative feedback from society rather than from the disability itself (Peterson, Ekensteen & Rydén, 2006). In a study by Williamson, Craig & Slinger (2008) concerning self-worth the authors found that peer approval was considered equally important to a group of children and adolescents with AS as it was to the TD group. The AS group was well aware of their rather small opportunities to receive peer approval but the authors found no support for the assumption that they should suffer from depression, anxiety or lower global self-worth than the TD group. (Williamson et al., 2008). Bauminger, Shulman and Agam (2003) examined the nature of peer interactions and loneliness in children and adolescents with AS and found that they understood the meaning of a close friend and could also define the emotional aspects of loneliness. This made the authors conclude that there was a discrepancy between the understanding of and the actual quality of the social interactions performed by individuals with ASD. The complexity of interacting seems to be hard or impossible to grasp. This was also supported by Howard, Cohn and Orsmond (2006) who concluded that it is important to understand that the deficits in social interaction skills and the challenges that individuals with AS experience should be separated from lack of interest. In most cases the desire to have friends and be able to maintain relations is just the same as in TD individuals. In a study by Jennes-Coussens, Magill-Evans and Koning (2006), a group of young men with AS reported lower social and physical quality of life. The physical domain comprised health issues, activities of daily living, energy and fatigue but also clumsiness and sensory hyper sensitivity. Clumsiness and DCD may decrease motivation to participate in physical activities and also lead to social shortcomings as was mentioned earlier (Miyahara & Piek, 2006). However, in ASD the social difficulties are part of the core symptoms and not primarily a consequence of clumsiness even if it may contribute to lower the sense of self-worth.

A high intelligence quotient (e.g. IQ over 130) in a young person with AS may raise self-worth as well as acceptance from peers and adults. It can also lead to the opposite and cause worse situations of isolation and alienation than those with average IQ and AS may encounter. Bullying of a person who is seen as a “nerd” is common and leads to low self-worth in the long run (Attwood, 2007). As has been indicated, positive self-perception and psychological adjustment seem to be linked together and an aspect of this is adaptive functioning. There is often a considerable discrepancy between intellectual ability and adaptive functioning in everyday life. Of all the problem areas that exist for individuals with AS the socialization domain seem to be the one that most often presents low scoring (Klin, Sparrow, Marans, Carter, & Volkmar, 2000).

When Mitchell and O'Keefe (2008) investigated how much young persons with AS and HFA knew about their own inner states concerning different topics of self-understanding, they found that the persons with the diagnoses did not understand that they were supposed to be the best judges of how they felt and were thinking. Instead they assigned the same amount of knowledge about themselves to another fictitious present person. There were however nuances; they were aware that the other person should be able to judge their inner states to a higher degree when they were happy than when they were daydreaming. When it came to concrete activities like knowing about a certain favourite TV program they were totally aware that they were the primary judge in relation to their favourite program and the fictitious person were the same in relation to his/hers. The study showed that it was difficult to understand and fully grasp the advantage of having first person access to one's own inner states (Mitchell & O'Keefe, 2008).

A protective factor for children, adolescents and young adults seem to be parental acceptance (Berenson, Crawford & Cohen, 2005; López-Justica, Martínez, & Medina, 2005; Williamson et al., 2008). In a study by Berenson et al. (2005) the parental acceptance correlated with their offspring's ratings of global self-worth, and it also did at a retest five years later. The authors found that identification with parents based on admiration and perceived similarity was a positive marker for successful attachment between parent and child. This may in many cases have an impact on positive self-perception and self-worth in young adulthood. In the Williamson et al. (2008) study the parental indulgence and understanding toward the child with AS promoted a positive mental wellbeing. Parental acceptance may be connected to early diagnosis. By minimizing the time gaps between the parental initial worrying, first assessment, and age of diagnosis the child might receive early intervention (Wetherby, 2008) and the parents would be able to feel that the child's problems are shared by others instead of only being their private concern.

## *Concluding Remarks*

There are several fields that individuals with AS have to struggle with and some of them were summarized by Holliday Willey (2003) who also has the diagnosis. They were difficulties with: inflexible and rigid thinking, making connections and generalizations, complex problem solving, abstract thinking, multi-tasking, expressing emotions, reading non-verbal messages, making sustained and appropriate eye contact, change in routines or transitions, and language and communications that goes beyond a literal level. When summarizing these and other problem fields individuals with AS live with a conclusion is that AS must be considered a complex and serious disability. The difficulties may be less pronounced than those in Kanner's autism but the amplitude makes them severe enough. The majority of the dysfunctions has an impact on social interaction, communication and, thus, relations to peers directly or indirectly. Forming an identity and a self-understanding could be a challenge for the individual. Since the characteristics of AS and ASD are often found in early infancy, knowledge about early markers is helpful for the children, the parents and the siblings, and an early diagnosis would contribute to early intervention which could change the attitudes from others.

## SUMMARY OF THE EMPIRICAL STUDIES

### General and Specific Aims

The purpose of the thesis was to explore aspects of behavioural and cognitive qualities of Asperger syndrome from both a parental perspective and from the perspective of young individuals with the diagnosis. More specifically the aims were:

- To find out retrospectively, according to the parents, if there had been any early markers of AS in infancy
- To find out about the quality and intensity of the repetitive behaviour in AS
- To analyse how the young persons with AS perceive themselves
- To explore what impact deficits in attention and in executive functions may have on AS
- To explore cognitive traits and understanding of social interaction.

### *The Studies*

*Study I.*
*Parental retrospective assessment of development and behaviour in Asperger syndrome during the first 2 years of life.*
The main purpose of the study was to investigate whether it was possible to find specific features during the first 2 years in infants who later received the diagnosis of Asperger syndrome. There seems to be a consensus among several authors that it is possible to make an early diagnosis of Kanner's autism in infants but not one of AS (e.g. Kleinman et al., 2008). The second purpose was to find out if a parental questionnaire, Symptoms of Autism before age 2 (SAB-2, Dahlgren & Gillberg, 1989), was a valid and reliable instrument that could be used retrospectively to trace features of AS early in life. These features might be complicated to interpret one by one but when found in clusters representing different categories a pattern could be visible and valuable for making an early diagnosis.

*Study II.*
*Repetitive behaviour and obsessive-compulsive features in Asperger syndrome: Parental and self-reports.*
Repetitive, ritualistic behaviour and intense or circumscribed interests belong to the core fearures in AS and the primary aim of the study was to explore the nature of these behaviours and their possible relationship to obsessive-compulsive disorder and to a co-occurring anxiety. The intention was to investigate the presence of specific features rather than to establish a level of possible OCD. A second purpose was to compare the young persons' and their parents' evaluations of the problem field during the school years and also to investigate the parents' experiences of their children's behaviour during the preschool years.

*Study III.*
*Self-perception and self-understanding in Asperger syndrome.* The aim of the study was to explore how adolescents and young adults with AS describe and perceive themselves globally, in relation to others, in relation to the past and the future, and their hopes and dreams, all in comparison to typically developing individuals.

*Study IV.*
*Attention deficits in Asperger syndrome.* The main purpose of the study was to investigate if adolescents and young adults with AS would show more of attention deficits than a group of typically developing peers. Since AS(D) and Attention Deficit (Hyperactivity) Disorder, AD(H)D, are considered to share traits and location in the neuropsychiatric field (Gillberg, 2002; Kopp, Kelly & Gillberg, 2009) a second purpose was to investigate if co-occurring features of AD(H)D would be present. The third purpose was to compare the parental and the youth evaluations in the AS and the C groups.

*Study V.*
*Social cognition and executive functioning in Asperger syndrome.* Compared to Kanner's autism there are usually relatively small characteristics that distinguish individuals with AS from TD peers. The characteristics and special features can be seen in various fields and situations and the purpose of this study was to pinpoint some of these cognitive traits with emphasis on social cognition and executive function.

# Method

## *Participants*

Two groups of adolescents and young adults ranging from 14 to 24 years of age and their parents were included, a group with Asperger syndrome (the AS group) and a comparison group (the C group) of TD young persons without any known disabilities. The participants with AS were recruited from schools with special classes for students with AS and from autism/Asperger societies in the west of Sweden. All participants in this group had previously been diagnosed with AS in the south or west of Sweden by experienced clinicians and had an IQ within the normal range. The diagnoses had been made 10-15 years earlier according to the criteria in the DSM-IV (1994) but also, since this is a Swedish sample, the Gillberg and Gillberg criteria (1989). The special classes for students with AS were situated in public schools and employed the normal curriculum. A majority of the special classes contained fewer students than the ordinary ones and in order to attend the student had to be properly diagnosed. The participants who did not go to school when the study was carried out had previously been students in either special classes of the same kind as the described or had, in a few cases, been part of ordinary classes. Some schools prefer smaller classes or a teacher's assistant instead of special classes when students with neuropsychiatric diagnoses need extended support. This was a model that some of the students who did not attend special classes participated in. A few did not receive any support at all. At the time of the interviews the older individuals had continued to study on high school level for adults or had an occupation in a more or less sheltered job. The participants in the comparison group, with no known disabilities, were recruited through posters, information in classes at various schools and by asking parents with adolescents or young adults of the age in question.

The two groups of young individuals and their parents participated in all of the studies described in the present thesis. The number of participants varied somewhat in the studies and in the different tests. Since the differences are small they are accounted for as a range measurement (*Table 3*). The reason for the variation in number of participants depended on the following: some of the participants were not sending back the questionnaires and the self-assessments but they participated in the tests carried out in a clinical setting, and technical problems with equipment (tape recorder and tapes) caused a small reduction of the participants. In a few cases the parents sent back their questionnaires but not the young persons and vice versa. The age distribution of the participating adolescents and young adults is shown in *Table 2*.

*Table 2.* The age distribution of the adolescents and young adults in the studies

| | Total number of participants | |
|---|---|---|
| | The AS group | The C group |
| Age of the participants | (N= 28) | (N = 14) |
| 14 | 2 | 1 |
| 15 | 0 | 1 |
| 16 | 4 | 2 |
| 17 | 2 | 2 |
| 18 | 10 | 2 |
| 19 | 4 | 1 |
| 20 | 1 | 1 |
| 21 | 2 | 1 |
| 22 | 0 | 2 |
| 23 | 2 | 1 |
| 24 | 1 | 0 |

*Table 3.* Mean age, standard deviation and number of adolescents and young adults in the studies

| AS group | | | | C group | | | |
|---|---|---|---|---|---|---|---|
| Number | | | Age | Number | | | Age |
| All | Males | Females | M (SD) | All | Males | Females | M (SD) |
| 23 – 27 | 18 - 22 | 5 | 18.52–18.68<br>(2.21 – 2.60) | 13-14 | 6 | 7 – 8 | 18.57 – 18.93<br>(2.84 - 3.16) |

Partcipants in *study I* were parents, in *study II* and *study IV* parents and adolescents/young adults, and in *study III* and *study V* adolescents/young adults.

## *Instruments and Procedures*

The test materials were selected to maximize both breadth and depth with respect to the different topics. The instruments to the parents were mailed or handed over to them in person, all at the same time and put in chronological order, from infancy to present time. The instruments concerning the adolescents/young adults were administered at *one* occasion and the self-rating questionnaires were handed over to them with short written instructions of how to fill them in and that it was *their* personal evaluation or opinion that was of interest. They were also told that their replies would not be judged as being right or wrong and that only the authors would have access to the material as long as their names were connected to it. The instruments used in the studies are accounted for in *Table 4*.

*Study I*

A self-rating questionnaire comprising 144 items, Symptoms of Autism Before the age of 2 (SAB-2) (Dahlgren & Gillberg, 1989) was used. The items were divided into 8 areas: Contact and social activity, Responses to sensory perceptions, Communication and language/speech, Food/feeding and sleep, Play and fixations/rituals, Movements and motor skills, Development and behaviour, and Early suspicions (that something was different or wrong with the infant). The parent(s) filled in the questionnaire individually. Beneath each of the 144 items in the SAB-2 questionnaire there was a 100 mm long line where the parent(s) put an X depending on how they valued the particular statement according to the child's behaviour during the first 2 years. The line was drawn between the two extreme points "did not apply" to the left and "applied" to the right. The exact position of the X on the line was measured (in mm). The SAB-2 also comprised a few open ended questions regarding age of the child when the parental concern began and reasons for this. Number of siblings was also investigated.

*Study II*

Two parental rating questionnaires were used; The Childhood Routines Inventory version 1.2 (CRI; Evans et al., 1997; Evans & Gray, 2000; Swedish version, Wigren & Hansen, 2003) and The Child Obsessive Compulsive Impact Scale (COIS; Piacentini et al., 2007).Two self-rating questionnaires were given to the young participants; The COIS with the same items as to the parents, only expressed in a different way ("did you have problems with…." instead of "did your child have problems with….."),and Beck Anxiety Inventory (BAI; Beck, Epstein, Brown, & Steer, 1988). The Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS; Scahill et al., 1997; Swedish version-revised, Valderhaug & Ivarsson, 2005) was performed as an interview. The CRI was used to assess repetitive, ritualistic and compulsive-like behaviours (e.g. "Act out the same thing over and over in pretend play") in children at about 2-6 years of age and comprises nineteen items in the original version and twenty in the Swedish one. Another nine items comprising social behaviour and formulated in the same fashion as the former ones were added by the authors of the study (e.g. "Seem uninterested in peers"). This was done in order to capture the traits seen in AS according to DSM-IV-TR (2000) and the Gillberg and Gillberg criteria for AS (1989). The behaviours of the child were rated on a 1-5 scale ("never"-"always"). The resulting score sums up from 19 to 95 in the original questionnaire, from 20 to 100 in the Swedish version, and from 29 to 145 in the extended version. Internal consistency of the original scale, as measured by Cronbach's alfa has revealed to be good (=.89) (Evans et al., 1997).

The COIS is a measure of obsessive-compulsive disorder related impairment containing 52 items with parallel and identical parent and child/adolescent versions. The questionnaire deals with psychosocial functions due to OCD symptoms at school (e.g. “Change clothes or shower in connection to gymnastics”), in social settings (e.g. “Be with people I do not know”), and at home/with family (e.g. “Go on holiday with my family”). The participants were asked to rate how much each one of the activities caused problems when the person in question was in the compulsory school age (about 7-16).The items are rated on a Likert 0-3 scale (“not at all”- “very much”). The score is measured from 0 to 156.

The BAI is a self-rating scale with twenty-one items designed to measure levels of anxiety in young persons and adults. The items comprise questions about how the participants have felt during the last week, expressed as common symptoms of anxiety. There are four alternatives to consider: 0= not at all, 1= mildly but it did not bother me much, 2= moderately, it was not pleasant at times, and 3= severely, it bothered me a lot. The scores range from 0 to 63 and are divided into four levels: (0) 0-7 minimal level of anxiety, (1) 8-15 mild anxiety, (2) 16-25 moderate anxiety, and (3) 26- 63 severe anxiety.

The CY-BOCS is a semi-structured interview designed to measure absence, presence and severity of OCD symptoms during the previous week among children and adolescents (Scahill et al., 1997). The scale also contains items concerning sensory perception like sensitivity to light, to sound, to smell, to the texture of food, and to the sense of clothes against the skin. The interview was used with the purpose to find every indication of obsessive-compulsive or repetitive/ritualistic behaviour amongst the participants and the experienced impairment associated with those behaviours. The participants were interviewed one at a time by the first author in a quiet room. The interview lasted for 30-40 minutes. Each interview was tape-recorded and transcribed. The participants were asked to tell the interviewer about any behavioural feature that they were aware of in themselves that could be relevant for the topic. Probes like “How do you mean?” and “Could you tell me more” were used when suitable.

The interview comprises 74 questions about obsessions (38) and compulsions (36), and another 26 questions to use as a follow-up when OCD could be suspected (Swedish version-revised, Valderhaug & Ivarsson, 2005). The answers to the questions were categorized and summarized to extract separate scores for obsessions and compulsions as well as a total score. Three levels were used: 0 = none, no incidence at all, 1 = seldom, not very much, mild incidence, and 2 = signs of obsessions and/or compulsions, moderate to severe incidence. The overall score is measured from 0 to 148 or 200 if all the questions were used.

*Study III*

Two tests were used; The Self-Understanding Interview (SUI; Damon & Hart, 1988) and The I Think I Am-questionnaire (ITIA; Ouvinen-Birgerstam, 1999). The SUI works like a two-part conversation with seven items asked and "discussed" in a fixed order. The items are: Self-definition, Self-evaluation, Self in past and future, Self-interest, Continuity, Agency, and Distinctness. The interviews were recorded and transcribed. The statements from the participants were then placed in either of the categories physical, active, social or psychological and subsequently counted. According to the intentions of Damon and Hart (1988) 'probe' questions should follow the principal questions in order to receive as much information as possible. These probes were excluded from the interviews in this study. Instead individual suitable probe questions were asked if needed. The reason for exclusion of the probes was that the participants were teenagers or older with an IQ within the normal range and keeping up a conversation based on their approach to the questions was thought to be more rewarding for the amount of information. The scoring procedure is based on units (or statements) that can be identified in the transcripts of the interviews (Damon & Hart, 1988). The scoring system was used with modifications to better suit the purpose of this study. Each unit in the interviews irrespective of which of the seven questions it belonged to was coded into one of the four categories: physical ('I am good looking', 'I have Asperger'), active ('I have good results at exams', 'I am an excellent swimmer'), social ('I am not a very social person', 'I am not the kind of person that do what others do'), and psychological ('I am not a romantic person', 'I am a quiet person'). No difference was made between positive or negative statements. The total amount of statements in each category was scored. After the first author's scoring, the second author scored 15 % of the statements. This was followed by a discussion where discrepancies were solved and the first author rescored the remaining statements accordingly. The statements were also analyzed beyond the statistical measures.

The ITIA is a Swedish self-report questionnaire for the study of self-perception and self-worth in children and adolescents. It is based on the assumption that there is a positive relationship between attitude toward oneself and mental health. The test consists of 72 items comprising five different categories. The categories are: Physical characteristics (14 items), Skills and talents (14 items), Mental wellbeing (16 items), Relations to parents and family (14 items) and Relations to other people (14 items). For each item the person is asked to consider in what way the item matches his/her thoughts about him/herself. There are four alternatives to choose between on the scale; from 'This is exactly like me' to 'Not at all like me'. It takes about 30 minutes to perform the test and the items are positively presented ('I have a nice face') as well as negatively ('I do not care how I look'). The alternatives are scored -2, -1, 1 and 2, depending on a predetermined value, and the complete test gives between -144 and 144 points. According to the manual higher scores are interpreted as higher self-worth. The instrument is originally composed for children 7-16 years but can be used for an older sample with minor corrections. The participants who no longer were students were for example asked to think back on how it was when they went to school. The ITIA has been used in both non-clinical (Ouvinen-Birgerstam, 1984) and clinical groups (e.g. Jemtå, Fugl-Meyer, Öberg & Dahl, 2009; Priebe, Hansson & Svedin, 2010).

*Study IV*

A parental and self-rating questionnaire was used; The Brown Attention Deficit Disorder Scale (BADD; Brown, 1996).The BADD aims at assessing the criteria for AD(H)D established in the DSM-IV (1994). It comprises not only hyperactivity and impulsivity but also deficits in executive function that may be present. The questionnaire contains 40 items divided into five categories: *1.)* Organizing, prioritizing and activating to work (9 items), *2.)* Focusing, sustaining, and shifting attention to tasks (9 items), *3.)* Regulating alertness, sustaining effort, and processing speed (9 items), *4.)* Managing frustration and modulating emotions (7 items), and *5.)* Utilizing working memory and accessing recall (6 items). The items are rated on 0-3 scales ("never" - "almost every day") and the score is measured from 0 to 120. Higher scoring means more problems. The BADD was used in two versions; one 12-18 years and the other 18 and older, depending on the age of the participants. The individual score falls into one of three levels with scores for adolescents younger and older than 18 years of age respectively in brackets: 1.) AD(H)D possible but not likely (<45 and <40), 2.) AD(H)D probable but not certain (45-59 and 40-54), and 3.) AD(H)D highly probable (>60 and >55).

*Study V*

Three tests from The Wechsler Adult Intelligence Scale-III (WAIS-III; Wechsler, 1997) were used; Digit span, Vocabulary and Comprehension. Executive function ability was tested by using The Wisconsin Card Sorting Test (WCST; Heaton, Chelune, Talley, Kay & Curtiss, 1981, Swedish version; Nyman, 1996). Social cognition was measured with two tests; Dewey's Social Stories (DSS; Dewey, 1991) and Stories from Everyday Life (SEL; Kaland, 2004).

The Digit Span Scale is divided into two variants; digits forward and digits backward measuring short term memory and working memory respectively. The test leader read one digit per second with an amount of three digits up to nine at a time in the forward variant and two up to eight at a time in the backward variant. Two series of digits with equal amounts were presented and the scoring was set to 2, 1 and 0 points depending on the participants succeeded to recall both, one or none of the two series with the same amount of digits. The scoring was 0-14 in both variants and 0-28 taken together.

The Vocabulary Scale comprises 32 words the participants should explain the meaning of. The scoring was set to 2, 1 or 0 points depending on the quality of the translation and the total score could range from 0 to 64 points. The test leader read a word aloud and the participant could read it from a list of words simultaneously. This was done because there may be various preferences in how to perceive a task most efficiently among the participants (i.e. vision or hearing).

The Comprehension Scale comprises 16 questions that should be answered orally. They deal with everyday problems, social "rules" and conceptions most people get in contact with. The scoring was set to 2, 1 or 0 points depending on the quality of the answer and the total score could range from 0 to 32 points. The test leader read the questions aloud and gave the participants enough time to deliver an answer they were as content as possible with. When necessary, a probe question like “Can you tell me more?” was asked.

A manual version of the WCST was used consisting of four stimulus cards and 128 response cards. The WCST is employed as a measure of executive functions comprising initiation of activity, planning, and keeping a chosen strategy to reach a goal. This also includes working memory. The participants must determine the correct sorting principle and then hold on to the principle until the set is finished, i.e. 10 correct responses in a row. The scores were based on the following: total number of correct responses, number of perseverative responses, number of perseverative errors, number of non-perseverative errors, number of trials to complete the first category, and completion of the categories or not. Three sets (instead of the stipulated 6) were decided to use (colour, symbol and quantity) because the test was part of a more extensive exploration of functions of the adolescents and young adults and it was necessary not to wear out the participants. The test is not time limited but those who completed it managed to do so in 15-25 minutes.

The DSS test consists of eight social scenarios, each of them containing a series of behaviours to be rated on a scale: A = normal behaviour, B = rather strange behaviour, C = very eccentric behaviour, and D = shocking behaviour. The number of behaviours on each story varies from 2 to 6. Dewey did not provide a quantitative measure but did qualitatively account for the result. Ellis, Ellis, Fraser, and Deb (1994) suggested a way of scoring the results: a group of adolescents and young adults without any known diagnosis filled in the instrument and their “model response”, i.e. the most frequent choice came to be the “correct” one. A deviation of one category was scored as 1, a two category deviation as 2 and a three category deviation as 3. As an example, if the most frequent response was “A” to a specific behaviour, a reply of “B” was scored as 1 error, a reply of “C” was scored as 2 errors, and a reply of “D” was scored as 3 errors. The participants in the present study were also requested to comment on the stories in writing which six of them did.

The SEL test material contains 26 short stories and 10 of them were used in the present study. The 10 stories comprise topics like lie, white lie, figure of speech, misunderstanding, irony, persuasion, contrary emotions, intentions, empathy and social blunders. There are several questions to be asked after reading the story in order to check if the participant understood the contents of the story and also the gist of it. Two crucial questions comprising physical (PI) and mental (MI) inference provide the base for the scores. The answer to the PI question could be found in the first part of the story and the MI question is asked in a fashion that forces the participant to draw a conclusion about a mental state in a social context. The scoring procedure is described as fully correct answers give 2 points, partly correct answers give 1 point and incorrect answers give 0 points. A prompt was given and questions like “How do you mean?” and “Tell me more” were asked when appropriate. Five of the stories (white lie, figure of speech, irony, persuasion and empathy) were read aloud by the test leader while the participant had a copy of the text in front of him/her at the same time. All the questions connected to each story were asked, recorded and written down. The other five stories (lie, misunderstanding, ambivalence, intention and social blunder) were part of a test "battery" that were sent home to the participants in order to fill in single-handedly. Then only the PI and MI questions were asked and answered in writing.

*Table 4.* The instruments used in the studies

| Instrument | Description | Person | Age (approx.) |
|---|---|---|---|
| Symptoms of Autism Before the age of 2 (SAB-2) (Dahlgren & Gillberg, 1989) | 144 items questionnaire | Parents | 0–2 |
| Childhood Routines Inventory (CRI) (Evans, Leckman, Carter, Reznic, Henshaw, King, & Pauls, 1997) | 20 items questionnaire + 9 items by the authors | Parents | 2–7 |
| The Child Obsessive Compulsive Impact Scale (COIS) (Piacentini, Peris, Bergman, & Chang, 2007) | 52 items questionnaire<br>Two versions | Parents + adolescents/young adults | 6 –16 |
| Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS) (Scahill, Riddle, McSwiggin-Hardin, Ort, King, Goodman et al., 1997) | 74 items interview + 26 additional items | Adolescents/young adults | Children, adolescents and adults |
| Beck Anxiety Inventory (BAI) (Beck, Epstein, Brown & Steer, 1988) | 21 items questionnaire | Adolescents/young adults | Adolescents and adults |
| The Self-Understanding Interview (SUI) (Damon & Hart, 1988) | 7 items interview | Adolescents/young adults | Children and adolescents (and adults) |
| The I Think I Am self report (ITIA) | 72 items questionnaire | Adolescents/young adults | Children and adolescents (and adults) |
| The Brown Attention Deficit Disorder Scale (BADD) (Brown, 1996) | 40 items questionnaire | Parents + adolescents/young adults | 12 – adults |
| The Wechsler Intelligence scale for adults- third edition (WAIS-III, Wechsler, 1997)<br>Digit span | Measures of short term and working memory | Adolescents/young adults | (Adolescents and) Adults |

|  |  |  |  |
|---|---|---|---|
| The Wechsler Intelligence scale for adults- third edition (WAIS-III, Wechsler, 1997)<br>Vocabulary | 32 words to explain the meaning of orally | Adolescents/young adults | (Adolescents and) Adults |
| The Wechsler Intelligence scale for adults- third edition (WAIS-III, Wechsler, 1997)<br>Comprehension | 16 questions about universal problems or concepts to be answered orally | Adolescents/young adults | (Adolescents and) Adults |
| Wisconsin Card Sorting Test (WCST) (Heaton, Chelune, Talley, Kay & Curtiss, 1981) | Measures of executive functions | Adolescents/young adults | Children, adolescents and adults |
| Social Stories (DSS) (Dewey, 1991) | Measures knowledge of social interaction | Adolescents/young adults | Children, adolescents and adults |
| Stories from Everyday Life (SEL)<br>(Kaland, 2004) | Measures ability of “physical” and “mental” inferences | Adolescents/young adults | Children, adolescents and adults |

### *Data Analyses*

All of the quantitative data were analyzed with Statistical Package of the Social Sciences (SPSS) version 17.0.

*Study I*

The one-way Analysis of Variance (ANOVA) was used to analyze the differences between the two groups. The α-level was set to $p<.01$ except for the 25 items with the most salient differences between the groups where the α-level was set to $p<.001$.

*Study II*

Descriptive statistics were computed for parent ratings on the CRI and on the COIS, and for youth ratings on the CY-BOCS, on the COIS, and on the BAI with computations of means and standard deviations. Differences between group means were analyzed with ANOVA. On the CRI a principal component analysis was conducted in order to describe the variability and to extract the main factors (Jacobsen & Pedersen, 1995) from the extended scale. The number of components extracted was determined by eigenvalues greater than 1.5 (Kaiser’s criterion). Factor loadings >.50 were interpreted as salient loadings. The components score were computed according to the regression method. The resulting score was used in the subsequent statistical analysis. An analysis of the individual items in order to find out which showed the most prominent differences between the groups was performed with the ANOVA on the CRI and on the COIS. On the CRI the factor scores were used. The α-level was set to $p<.01$.

*Study III*

One-way ANOVA was used to analyze the differences between the two groups in the two tests, SUI and ITIA. The α-level was set to $p<.05$. Analysis beyond the statistics was also performed in The SUI.

*Study IV*

On the BADD means and standard deviations of group differences of the results on parental and self evaluations were conducted on the whole test and on the separate categories. Group differences were also assessed by means of ANOVA with $\alpha < .05$. Partial Eta Squared was accounted for in order to measure the size of the effect. A percentage evaluation of the severity of the reported AD(H)D symptoms according to BADD was made. Since the t-score was accounted for in the test those measures were also considered and thus accounted for.

*Study V*

Descriptive statistics were computed for ratings on all of the instruments (Digit span, Vocabulary, Comprehension, WCST, DSS, and SEL) with computations of means and standard deviations. ANOVA with $\alpha < .05$ was used and also $\chi^2$ in order to measure possible significances on the scoring of the groups and frequencies of distribution of the scores.

## Main findings

*Study I*

Regarding early symptoms there were significant differences between the AS group and the C group in all fields except “Early suspicions”. The fields “Food/feeding and sleep” and “Contact and social activity” were found to be the ones that caused most concern. In each of the seven fields there were some items that revealed a higher statistical difference than the rest (i.e. α-level $p<.001$ instead of $p<.01$) i.e. 25 items (of 144). Eight of the items belonged to the field “Contact and social activity”, 4 items belonged to “Play, fixations, and rituals”, 3 items belonged to “Communication and language/speech”, “Sensory perception” and “Food, feeding, and sleep” respectively, and 2 items belonged to “Movements and motor skills” and “Behaviour and development” respectively. The range of the evaluation scores within the AS group was greater than that within the C group (e.g. in the field “Behaviour and development” the parents ratings ranged from 1.49 to 9.60 in the AS group and from 0.78 to 2.33 in the C group). The greatest within-group differences could be seen in the fields of “Play, fixations and rituals”, “Food, feeding and sleep”, and “Behaviour and development”. Six of the items from 3 of the fields that were evaluated most alike by the parents were also noted. These were found in “Play, fixations and rituals” (Liked to constantly turn the lights on and off, Liked to constantly open doors and shut them, and Loved to look at the leaves in the trees), in “Movements and motor skills” (His/her movements were agile and graceful and Once s/he started to walk s/he did it perfectly at once), and in “Responses to sensory perception” (Sometimes the sound of something made him/her cover the eyes instead of the ears).The additional open ended questions revealed parental awareness of the children’s anomalies at an early age and of the 21 parents to children with AS who replied to the questions 19 had more than one child.

*Study II*

The results on the COIS self- and parental reports revealed significant difficulties with repetitive, obsessive-compulsive features, and social interaction during the school years. This was also evident during the preschool years as reported by the parents on the CRI. There was however no difference between the AS and the C group on the CY-BOCS interview indicating that the behaviours in the AS group that caused an amount of problems during childhood and adolescence at school, in most social settings and also at home was not related to obsessive compulsive disorder symptoms as described in the DSM-IV (2000). Another finding was that when comparing the COIS parental and self-reports, the parents to the young persons in the AS group scored higher, and thus revealed more problems, than their children while the opposite was the case in the C group.

None of the groups showed any signs of anxiety according to the BAI. The only significant result in the BAI questionnaire was the item; "hands trembling" where the AS group scored higher than the C group. When comparing how the scores were divided within the groups considering the levels of anxiety the result showed the following: In the AS group 45.1 percent belonged to level 0, 41.7 percent belonged to level 1, 12.5 percent belonged to level 2, and none belonged to level 3. In the C group 61.1 percent belonged to level 0, 30.8 percent belonged to level 1, none belonged to level 2, and 7.7 percent belonged to level 3.

*Study III*

The differences between the groups when it came to self-perception and self-understanding were relatively small but noticeable. The participants in the AS group described themselves with similar amount of statements as the C group and they expressed knowledge about themselves to an equal extent as the TD participants. However, there were differences in the way the two groups expressed and described themselves which became obvious in the SUI. The quantitative measures showed few differences between the groups, while a further analysis of the responses to the interview questions revealed distinct differences between the groups. Out of the four categories physical, active, social and psychological, only in the active category difference was found. The AS group used significantly fewer statements about activities like playing instruments, singing and sports. They were also less inclined to plan or dream about going abroad or move to another country. Two items in the SUI showed significant differences between the groups. On item 7 (distinctness), in the physical category, the C group made no statements at all about their physical distinctness from others compared to the AS group. The individuals in the AS group stated e. g. that the diagnosis was something that separated them from other people. On item 5 (continuity), the AS group produced fewer statements than the C group in the active category. The participants in the C group reported for example that they changed from one year to another because they became more successful in sports or were active working with student democracy. There was no significant difference in the total amount of statements from the participants.

The ITIA questionnaire revealed an overall significant difference between the two groups and in the analysis of the five categories the AS group scored lower on four of them, however not significant. The only significant result that could be seen was in the category “Relations to other people”. Higher scoring means better self-worth according to the design of the test. Six of the 72 individual items revealed significant differences with lower scores from the AS group. Of the 6 items 3 belonged to the category “Relations to other people”.

*Study IV*

The BADD questionnaire showed a significant difference between the AS and the C groups ($p < .001$).The young individuals with AS revealed more symptoms of attention deficits and problems with executive functioning in all of the five categories, in the questionnaire, than the C group did. Both the parents and the young individuals scored significantly higher than the C group on all categories with one exception: category 4 “Managing frustration and modulating emotions”. The participants in the AS group considered themselves to have little or no problems with handling frustrations and emotions which was not agreed upon by their parents. According to the BADD, two thirds of the participants with AS showed possible or reliable signs of AD(H)D. This result was even higher in the parental report. In the C group the parents scored lower than their children. The purpose of the study was not to diagnose the young persons with a co-existing disorder but since the BADD scale gives information about possible outcome for AD(H)D the result could be interpreted as those who received high scores might have moderate to severe problems with attention.

*Study V*

There were small differences when assessing the entire “battery” of tests. The only significance on a whole test was on the Digit span ($p = .005$). The Vocabulary and the Comprehension test showed slightly higher scoring from the C group ($p = .45$ and .065 respectively). In the WCST five participants in the AS and four in the C group did not complete the test showing that problems in executive functioning ability was not, in this case, connected to the AS diagnosis. The same could be said about the social stories in the DSS and the SEL. Significant differences could be discerned in two stories (SEL) comprising white lie and empathy. These two items proved to be more difficult for the individuals in the AS group than those in the C group. In the DSS two of the stories showed higher “error” scores from the AS group indicating that the young persons found the behaviours relatively normal while the C group considered it rather strange or eccentric.

# GENERAL DISCUSSION

The primary aim of the thesis was to investigate and describe aspects of behavioural and cognitive features in Asperger syndrome in infancy and in adolescence and young adulthood from a parental retrospective and current view and from the perspective of the individuals with the diagnosis. Repetitive behaviour, attention and social cognition were of particular interest. A more specific aim was to investigate the possibility to retrospectively find signs of AS in infancy, and another was to explore how the young persons with AS perceived themselves. The final aim was to compare the young persons' and the parents' evaluations regarding the young persons' behaviour when the same kind of questionnaires were distributed to them.

The overall result revealed that several of the well known problems in AS, according to the DSM-IV (APA, 2000), the Gillberg criteria (1989) and the literature, proved to be problematic also in the present studies. However, in some cases no differences were found between the AS and the TD groups, e.g. in the social cognition tasks and those that tapped capacity in a certain kind of executive functioning.

Skär (2003) found that the disability in itself (in her study restricted mobility) had little impact on how the persons conceptualize themselves. In the present thesis it seemed that the diagnosis was important to mention by the participants, regarded as a substantial part of their personality and in many cases a source of pride or contentment, but also in a few cases a burden.

## *Social Functioning*

Often persons with AS, despite high IQ, have difficulties in understanding how others think and feel and this may partly depend on the fact that in infancy and as toddlers, they seldom engage in the same things as others and, thus, do not develop the attentional ability to recognize what humans are attracted to in everyday life (e.g. Gillberg, 1997). With this in mind, it was unexpected and even surprising that the young participants with AS managed equally well on the social cognition tasks in *study V* as the comparison group.

Communication problems and language difficulties are, as have been mentioned, criteria in the Gillberg and Gillberg criteria of AS (1989) (speech and language peculiarities). However, "impairment in social interaction" is included in both of the diagnostic criteria used in the thesis and mime, gesture and body language could be said to belong to this field. These were also features that were reported as deviant. In *studies I* and *II* it was a main theme in the retrospective assessments made by the parents that the young persons with AS had severe problems with social interaction in day care facilities, at school and in other social settings. This was also present in adolescence and young adulthood as reported in *study III* by the young persons. An early diagnosis or not; the difficulties and the parental awareness were present the whole time.

In the ITIA questionnaire the three most discriminating items were found within the field "Relations to other people" and this was also the only category where a significant difference was found in comparison with the TD group even though the test as a whole revealed a significant result.

The COIS self- and parental reports have been produced as instruments for measuring OCD related features but because of the nature of the questions it is possible to use them in order to find other problems in social settings. Thus, such information can be useful for parents and young persons who experience difficulties, for instance, in getting started to go to school or to have lunch with peers, but not necessarily possess obsessive-compulsive features. The result showed considerable problems in, among other things, friendship and interaction with peers. As Gillberg (2002) has pointed out; persons with AS seem to lack the ability to interact intuitively in a flexible fashion with others and it will persist as they grow up. This could be perceived by others as an almost complete deficit of “natural improvisation skills”. A deficit like this could cause misunderstanding when to respond to comments comprising sarcasm, deception and lies, which has been noticed in the literature (e.g. Frith & Happé, 1999; Konig & Magil-Evans, 2001). The authors also concluded that when exposed to social tasks, persons with AS approached those in a way that was described as to “resemble slow, conscious calculation” (p. 7). The calculating approach proved to be successful since the results in social tasks in *study V* was equal to those of the C group. The 10 stories in the SEL comprised topics like lie, white lie, figurative language, misunderstanding, irony, persuasion (with a hint of manipulation), contrary emotions, intentions, empathy, and social blunders, and it was only on white lie and empathy the results showed lower scoring for the AS group. There could be different reasons for the good result. The SEL may not measure the desirable features, the stories were too simple to misunderstand, or the young persons with AS have learned to look at and solve all kinds of tasks in the same fashion; with slow conscious calculation. This model seems to lead them right, at least in theoretical situations. Some of the participants in the AS group waited for what they called “the punch line” in the SEL and when it was delivered they approached the task by discussing the intention behind. Why did they then misunderstand the white lie and the empathy stories? A suggestion was that those two topics add an extra feature that goes beyond the plot. The white lie was not an ordinary lie to avoid an unpleasant situation (for oneself) but instead an action to protect and care for a loved one (in this case a grandchild) who should not need to worry about unnecessary things. The case was the same for the empathy story; the participants did understand that a tired mother became angry with her ruthless son, but they did not realise that she was disappointed that he could not see the whole situation and show the consideration she felt she deserved. The relation between the characters was of importance in both cases and it was obvious that these two topics were more difficult to grasp for individuals with a different cognitive style or an unusual profile of cognitive abilities (Happé& Frith, 2006; Attwood, 2007), because of its complexity.

Some authors (e.g. Klin et al., 2004; Ponnet et al. 2004) have suggested that persons with ASD and normal IQ who perform well on tasks that require social reasoning ability often do so because all available facts are presented to them in a narrative form and they have time to consider possible options. In a “live” or naturalistic situation that requires spontaneous and fast reactions it becomes more obvious that their ability generally is weak. Thus, an IQ within the normal range is a valuable asset but

Dahlgren (2002) indicated "that children with [high-functioning] autism and children with Asperger syndrome are not helped by their relative competence in solving theory of mind tasks in linguistically complicated communicative situations". The main reason for the successful result on social tasks in the present thesis could be that the stories were logical in the composition of the plot, *one* person read the story (which also could be read simultaneously by the participant), there was no "hidden" messages based on glances, tone of voice or atmosphere, the narratives were held in relatively simple words, and the actions in the stories happened one at a time.

### *Self- perception*

In the extended analysis of *study III* and self-perception the more subtle differences between the groups became apparent. In many cases the participants with AS used flamboyant statements to describe themselves instead of the more "humble" ones from the participants in the C group. Examples of this were "I think I am rather smart compared to most people" and "I have a huge personality" when making a self-definition compared to "I enjoy being with others", a common remark from the C group. When describing what they were *not,* negative statements like "I am not somebody who is able to help people in a long perspective" and "I am not the dating kind" could be heard instead of the C group's inverted positive statements; "I am not somebody who hurts other people" and "I am not someone who gossips". Having an AS diagnosis was mentioned several times by the young participants and in most cases with pride but also with sadness in a few cases. To at least some individuals it had become a part of the identity that might be useful and important. When categorizing the statements by the participants a comment like "I have AS" was classified as a physical statement because of the impression that it was thought of as a personal characteristic like "I am tall". This could of course be discussed. In a study by Skär (2003) of adolescents with restricted mobility none of the participants mentioned their disability when describing and identifying themselves. This might depend on the fact that the disability was obvious because of wheelchairs and other devices so there was no need to draw more attention to it. The reason for the participants in the present study to talk about the diagnosis and on the whole be straightforward with their opinions might be connected to a manner of "truth telling" (Gillberg, 1997) and lack of understanding that it would be an advantage to present oneself in the best possible fashion (Begeer, Banerjee, Lunenburg, Terwogt, Stegge, & Rieffe, 2008). This also raises the question of how persons with AS use their language ability. Shortage or lack of friends and other relations may have limited the chances to chit-chat and gossip with peers and learn more appropriate ways of describing oneself and to fit in. When interviewing the young persons with AS they seemed to use less of "youth expressions" that TD peers use in their everyday language. In both SUI and ITIA problems with finding friends and lack of friends were prominent items. The item in the ITIA that most saliently separated the groups was "I have lots of friends". The participants in the AS group did not have lots of friends and the C group did. Long-term close relationships are unusual for individuals with AS according to Tantam (2000) and it was obvious that a majority of the young persons in the AS group had been bullied for long periods at school which seem to be the case for many individuals with AS (e.g. Attwood, 2007; Gerland, 1996; Jackson, 2002; Sainsbury, 2009). None of them talked about a particular friend who meant something special to them. In general it was more like descriptions of mates or acquaintances. This is one of the core symptoms in AS and is explained as “difficulties interacting with peers” in the Gillberg and Gillberg criteria (1989) and as “failure to develop peer relationships appropriate to developmental level” in DSM-IV(TR) (APA, 2000). In many cases it is possible that the young persons with AS create an identity of their own; one that is based on the diagnosis and the strong sides of the personality that they want to emphasize (Grandin, cited in Wallis, 2009). On the other hand, they were surprisingly eager to tell about their more obscure characteristics like “Since I am a bit dry and boring......” and other problems that might be perceived negatively like memory problems and inability to handle money.

The vocabulary that the participants used when talking about themselves mirrored self-worth and reasonable satisfaction with their lives. When for instance the participants stated that they wished it would be easier to find friends (now and in the future) none of them mentioned that they wished to be better at *making* friends, i. e. to increase *their* ability to appeal to peers. In one case the diagnosis was mentioned as a hindrance for being with others. Their descriptions and thoughts of themselves of being intellectual and philosophical (“I am very much like a scientist”) might also help to increase self-esteem and belonging to a crowd with high status. Attwood found that a high IQ or special skills could raise the status for the persons (2007) even if it did not automatically raise the amount of friends.

Self-compassion is considered to be a predictor of mental health and a treatment target for adolescents who hold negative views of themselves (Neff & McGehee, 2009). A way to alleviate for the individuals with AS to feel reasonably pleased with themselves is to “allow” them to blame some of their difficulties on the diagnosis (e.g., Punshon, Skirrow & Murphy, 2009). One participant uttered in the SUI that it had been important for him/her to receive the diagnosis at an early age because it would have been very difficult to accept it during puberty. The participant thought that during the teenage years s/he would be too sensitive to handle the burden of a diagnosis that had not been a part of the identity earlier. Even if the full impact and understanding of the diagnosis does not occur until in the middle or late teens, a chance to identify with it and accept the diagnosis (without letting it rule one’s life) and others who are in the same situation may decrease the risk of mood disorder and loneliness (Heyman, 1990).

### *Ritualistic Behaviour and Anxiety*

Play and imaginative activities have been found to be associated with repetitive behaviour in children with ASD indicating that children with few obsessive-compulsive features are more prone to engage in play activities than those who frequently engage in such behaviours (Honey, Leekam, Turner, & McConachie, 2007). A ritualistic behaviour may sometimes depend on the inability to create internal ideas and solutions. It may make a person do the same thing over and over again because s/he in unable to figure out a more appropriate solution (Gerland, referred to in Bejerot, 2002) and thus use one’s imagination. Difficulties with imagining things that are not real and had not happened yet are common. Many individuals are inclined to say “no” to proposals from others rather than “yes” because they are not certain of what they agree to even if they have a theoretical understanding of the activity. This may also have a negative impact on peer relations.

In the “Play, fixations and rituals” field of the SAB-2, it was commonly reported by the parents that s/he “did not play like other children”. The children, later diagnosed with AS, only played with certain objects and showed strange attachment to odd objects. This could be seen as narrow interests described in the Gillberg and Gillberg (1989) criteria and restricted repetitive patterns of interests (DSM-IV (TR), APA, 2000). It was obvious that the features that were more or less established in the first two years also could be found later during the preschool and school years and during adolescence and adulthood as measured by some of the tests. In *study II* the difficulties proved to be substantial as measured by the CRI and the COIS but even if the children in the AS group were dependent on rituals and repetitions and demanded sameness, no signs of obsessive compulsive disorder could be seen as measured by the CY-BOCS. The fact that the repetitive behaviour did not cause co-occurrence of anxiety or OCD could mean that it is a part of the ASD syndrome that has little to do with obsessions and compulsions in its most handicapping form. Instead the behaviour possesses the function of being pleasant (e.g. Gerland, 1997; Jackson, 2002). However, studies have found that repetitive behaviour in children, adolescents and young adults could be experienced as negative and distressing (South, Ozonoff & McMahon, 2005). The few obsessive-compulsive traits that were found in the AS group were equal to those in the C group and also; they were perceived and reported equally negatively.

The anxiety scale (BAI) showed no differences between the groups. According to Attwood (2007) it happens that young persons with AS are unaware that the discomfort they experience could be related to anxiety. However, nothing in the present study implied presence of anxiety.

### *Attention, EF, Sensory perception, and Motor ability*

In *study IV* it was found that the young persons in the AS group suffered from attentional problems, in many cases as severe as individuals diagnosed with ADHD according to the BADD. When looking at the SAB-2 in order to find early indications of co-existing features the items that could be a marker were a suspected hearing deficit, “s/he did not listen when spoken to” and also the items concerning ritualistic behaviour and routines. The majority of these items showed that attentional deficits could be found in infancy according to a retrospective perspective by the parents. The BADD claimed to measure attention and EF which also the WCST in *study V* did. Obviously the tests did not measure the same parts of EF or the difference became distinct because of the nature of the tests. In the BADD, questions were asked about the perceived situation in a broad perspective and in the WCST the participants had to perform here and now. The expected outcome on the WCST was worse result in the AS group since EF on the whole is seen as a problematic field (e.g. Zandt, Prior & Kyrios, 2009). The result was instead non-significant, a few participants from each group failed to pinpoint the rules, but those who did pinpoint them performed well. A reason for the good result in the AS group could be, just as in the social tasks, a calm environment without being interrupted. Being “allowed” to concentrate on one single task at a time offers good prospects to succeed.

In *study III* the young persons with AS reported sensitivity in relation to sensory perception above all in the auditory field but also in the visual field, in sensitivity to odour, texture of food and how clothes felt against the skin when wearing them. It seems that the unusual pattern of perceptual experiences in infancy that was retrospectively reported by the parents also was present in adolescence and young adulthood. Since the participants were aware of their problems they could also avoid unpleasant activities and places by removing ticking clocks, strong white light, and certain odours.

Problems with movements and motor skills were also found in the SAB-2 and were described as difficulties with imitating movements and being clumsy and ill-coordinated. Such problems were also commented on by Wing (1981) and in the Gillberg and Gillberg (1989) criteria but not in the DSM-IV. In the field of "Movements and motor skills" in *study 1,* the parents of the young persons with AS retrospectively reported difficulties with imitating movements, clumsiness and bad coordination. In the SUI the participants with AS reported negative attitudes towards sport activities. This could have caused difficulties with play and keeping up the pace with peers. This field showed to be problematic in infancy as well as later in adolescence/young adulthood which may give an indication that the difficulties remain stable in a life perspective.

Further, feeding and sleeping problems were reported as common during the first 2 years. According to Attwood (2007) the feeding difficulties may be connected to a sensitivity to taste, smell or texture of the food. Sleep disturbances also seemed to be a common feature. In the present study lack of calmness in sleep was reported. Short sleep duration and sleep onset problem has been seen in other studies along with sleep-related fears and negative attitude toward sleeping (Dickerson et al., 2009; McConachie et al., 2005; Paavonen et al., 2007). No present sleeping or food problems were reported by the young persons in the study. Hearing impairment was in some cases suspected and it was common with strange reactions to sound, as if certain sounds were painful. This has frequently been reported by parents (Gillberg, 2000). The perceptual sensitivity regarding sounds like ticking clocks that was reported in *study III* might be a remainder of these reactions to sound, and also, in some cases the attentional deficits reported in *study IV* might be due to an attempt to turn off unpleasant sounds.

### *Parents*

Parents are a common denominator in the *studies I, II, and IV*. They have had an impact on their children's wellbeing and have been aware of behaviours that did not fit the common pattern from birth and onwards. In the literature they are described as a protective factor (e.g. López-Justica et al., 2005). For the individuals in the AS group the parents were even now in adolescence and young adulthood more important than for the individuals in the C group and also more present in their lives. They were in many cases an alternative to peers because they prevented the adolescents and young adults from being too isolated. The negative side of closeness with parents when one is grown up is that there might be too much support and too few demands and challenges. There may also be lost opportunities to quarrel, discuss things and laugh at the same things as one's peers. Since the young persons in the AS group seemed to be aware of their problems and deficits it is also possible that these have been defined more or less entirely by the parents. How the parents on the whole have been able to cope with this special parenthood was beyond the scope of this thesis but it is worth noting that parental stress, especially for mothers, is correlated with severity of the disability of the child (Epstein, Saltzman-Benaiah, O'Hare, Goll & Tuck, 2008). The authors concluded that the challenges of parenting a child with AS should not be underestimated.

### *Diagnostic issues*

Wing (1996) pointed out that in some cases a child may have apparent characteristics that meet the criteria for autism during infancy and then, some years later the child instead meets the criteria for AS. The main theme in *study I* was to find out if it might be possible to diagnose a 2-year old (or younger) with AS. According to the SAB-2 results it was. Some of the children in the sample might have met the criteria for autism in infancy but it is hardly so that the whole group of 24 participants was affected to this extent. An advantage with the SAB-2 is that since it is possible to grade one's replies on a continuous scale, the parents should be more inclined to "admit" certain problems concerning their child. Thus, there is little risk for underestimations of the behaviour but instead could overestimations be the result.

Of the 25 (out of 144) items in the SAB-2 with the highest statistically significant differences between the AS and the C groups 8 items belonged to the field of "Contact and social activity" which made it the most problematic field for the children with AS. The items comprised eye contact, contact in general and isolation. The parents reported that the children did not seek out contact or attention from adults like their TD peers. However, the item "The child often turned to adults for contact" was scored equally in the two groups. Apparently, the frequency of contact was within the normal range but the quality might have been different. In the field "Communication and language/speech" the parents felt that the children in many cases were unable to communicate what they wanted and showed little attention toward the communication partner. According to the DSM-IV(TR) (APA, 2000) criteria no language delay should be part of the AS diagnosis but it seems that the parents found peculiarities even during the period of "babbling", i. e. before the verbal language development started.

The many similarities between the results of the Dahlgren and Gillberg study (1989) and the results in the present study indicate that there are similarities between autism and AS and the two diagnoses are undoubtedly situated on the same continuum. In the Dahlgren and Gillberg study the authors compared a group with autism, a group with mental retardation and a group with TD children. Of the 25 items with the highest parental scoring in the present study, 10 items coincided with the 18 items with the highest score from the parents to the children with autism in the Dahlgren and Gillberg study. These 10 items were mainly found within the field of "Contact and social activity" but also "Play and fixations/rituals", "Responses to sensory perceptions", "Movements and motor skills" and "Sleep". Lack of curiosity about the environment in childhood should not occur in AS according to the DSM-IV(TR) criteria (APA, 2000) but in this study the parents scored high on this item. In the long run it might affect the social development negatively which might be another reason for difficulties with finding and keeping friends as described in *studies II* and *III.*

Two thirds of the parents reported that they had suspected there was something wrong with their child before the third birthday, and in many cases long before that. This was consistent with the study of Howlin and Asgharian (1999). The reason for noticing that “something” was wrong could be deviant or strange behaviour and slow or delayed general development. Feeding problems and attention deficits were also reported. The older children, 3-6 years of age, showed difficulties in social interaction with peers, deviant language development and odd verbal manners.

McConachie et al. (2005) suggested that one reason for not giving a diagnosis to an infant is that the variety in the typical development must be considered. It is difficult to find a balance that both maps the difficulties and intervenes adequately at preschool and school and allows the typical development to vary. However, the children who much later receive a diagnosis had their particular problems already at this early point. An advantage of receiving an early diagnosis is that a child may avoid being seen only as a problem child in day care and at school but hopefully could look forward to a more calm and pleasant stay. An understanding from others during the early years may, with considerable luck, continue to be present through the school years. According to Peterson (2006) the attitude from others has a greater impact on the individual than the disability itself.

When discussing the advantages with an early diagnosis (e.g. Barnhill & Myles, 2001; Perry, 2004; Wing, 1996) the stability of the diagnosis is an important issue. It has been found to be high (e.g. Turner, Stone, Pozdol & Coonrod, 2006). However, it is not uncommon that the symptoms may change from one time to another. Repetitive behaviours are often more elaborated by the age of 4-5 than by 2 years of age (Moore & Goodson, 2003) and it seems that autism is a more stable diagnosis than PDD-NOS (Stone et al., 1999). A reasonable supposition is that some children with AS are diagnosed with PDD-NOS when first receiving a diagnosis. It may not be the most important issue that the precise diagnosis is given but rather to pay attention to the child’s difficulties and where they might lead.

A conclusion when identifying autistic traits could be that it may not be necessary to elaborate specific instruments for diagnosing AS compared to autism. Instead it is important to cover as many fields as possible that can be affected by the disorder and also to give the opportunity to reply on a continuum and to avoid yes/no alternatives. Even if the parents would prefer an AS diagnosis instead of one of autism, it is above all most important that the child receives support and suitable interventions. Wing’s (1996) way of describing ASD as a continuum and that the diagnosis may change should make it a little less dramatic to diagnose young children. A diagnosis could be seen more as a here-and-now report than a life sentence. It also happens occasionally that children lose their diagnosis as in the Sutera et al. (2007) study where a group of children received an ASD diagnosis at the age of 2 and lost it at the age of 4 without any differences in symptom severity between them and other children who kept their diagnoses. This shows that even if a diagnosis in most cases is stable and reliable it may also have the impact of a more short-term evaluation which is part of the variation in both normality and disability.

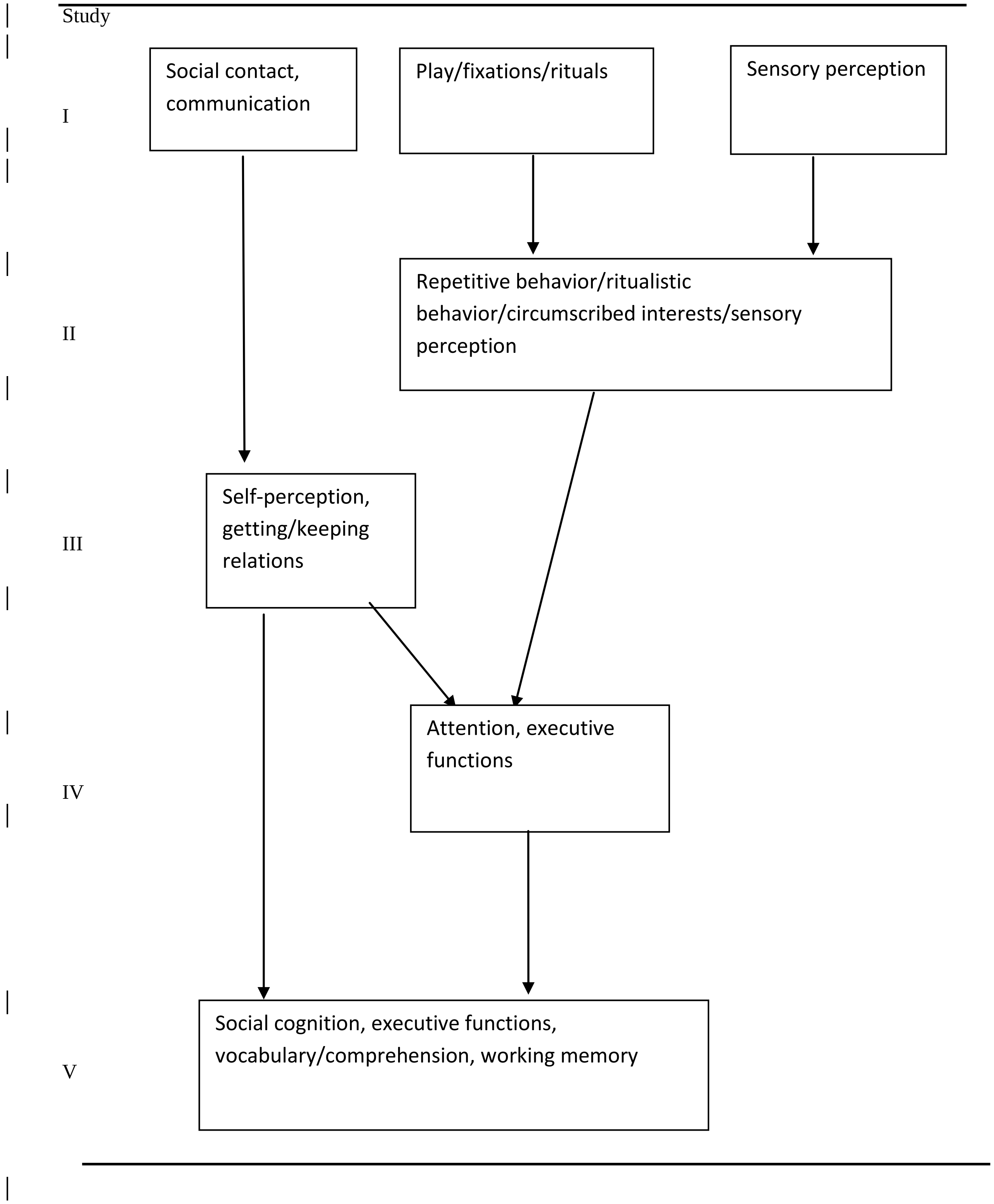
Surprisingly, some items in the SAB-2 were assessed very similarly by the parents to children in both groups even if the items belonged to the diagnostic criteria in DSM-IV (TR) (APA, 2000) for AS. The items “Did not smile when one expected him/her to” and “Would point to objects with the whole of his/her hand” could be regarded as social activities. The items “Liked to constantly turn the lights on and off” and “Liked to constantly open doors and shut them” could belong to the restricted, repetitive patterns of behaviour and activities that could be seen in TD children as well as in children with ASD (Evans, Gray, & Leckman, 1999). The items could also be seen in individuals diagnosed with Kanner’s autism. None of these items, however, seemed to have caused worries for any of the parents in *study I*. This indicates that a questionnaire like SAB-2 could be of help to understand the special features of the whole autistic spectrum better and also of what could be expected in the behaviour of TD children. A few behavioural peculiarities are experienced by all parents but clusters of them and high scoring in a majority of the items is a different matter.

When looking at the results of the studies in relation to the proposed changes in the DSM-V (DSM-V: The Future Manual, APA, 2011) it seems that clinically there are few benefits in differentiate AS and autism, especially if the severity level also will be a part of the autism diagnosis. There seems to be a reasonable agreement among researchers that AS and autism are situated on the same continuum. Since the differences are small and easily could be parts of the same criteria, the diagnosing procedures could be more reliable if the need to decide which diagnosis should be made is ruled out.

### *A model of the studies*

When exploring the group through several studies and then scrutinizing each task and result, it became obvious that the topics and criteria of the diagnosis communicate. Figure 1 illustrates the distribution of the topics in the thesis and the topics that caused concern in infancy did still did at later points. Considering the reported difficulties at earlier points the results in *study V* were unexpected since no difficulties with social cognition or EF other than working memory were found. It is possible that a developmental change or maturation has taken place or the instruments may not have been subtle enough to detect problems in these fields. If a parental evaluation of social cognition in the adolescents with AS had been made possibly another result on the topic would have emerged. Being a part of a social situation is more difficult than understanding it as a “dilemma” in a quiet setting when one is only a spectator.

*Figure 1.* An illustration of the different topics of the studies how they are presented and interact.



## *Methodological considerations and limitations*

The same group of young persons and their parents participated in all five studies and the youths were tested on *one* occasion. The main reason was that several participants lived outside Gothenburg and it was uncertain if they could participate within reasonable time again. This might have had impact on the results. First of all, it was important not to linger too long on a single task in order to exhaust or bore the participants. It is possible that more information had come out of, for instance, the CY-BOCS or the SUI interviews if more time had been spent on them. It is also possible that more probe questions had removed some of the spontaneous reactions and caused impatience from the young persons. Another risk could be spill-over effects from one area to another when performing many tasks at the same time. This is of course difficult to assess but the tasks were very different from each other which could have prevented the individuals from getting too acquainted with them. Using the same group throughout the thesis could be both advantageous and disadvantageous for the outcome. The advantages are that all the tests could be considered “equal”, i.e. the severity of the syndrome and the IQ do not vary between conditions. The disadvantages, on the other hand, could be that it may give a too narrow “picture” of the diagnosis and there is risk of having got a sample with specific features. The parents’ recollection might be too dependent on how experienced they are in describing their child’s behaviour. They might also give their ratings in light of the diagnosis that has been made.

All the tests based on retrospective data should be interpreted with caution since memory may be a somewhat deceitful source. The participants with AS were diagnosed 10-15 years ago and one can take for granted that most of the parents have learned a great deal about AS since then. They have also probably had more than one clinical contact which has made them more used to describe their children in every possible aspect than parents to TD children. It is therefore a possibility that their descriptions and memories could be of different quality. On the other hand; parents who have experienced problems or worries connected to their children probably remember those specific features and report them irrespective of a present diagnosis or not.

Since the participants were diagnosed a rather long time ago they were relatively “unused” in research which made the results more valid. The chosen instruments were new to the participants so no effect of practice should be present.

A major problem with the studies is that the groups are unevenly distributed when it comes to number and gender. This depended on unexpected difficulties with finding TD participants and specifically males. As time passed it was necessary to start the project and the design made it impossible to gradually find more TD participants. This may have made the differences more pronounced than if proper matching had been executed. However, the perhaps most crucial topic, social cognition, showed only minor differences between the groups in *study V*. If, as often is suggested, females are more skilled in social interaction than males and individuals with AS are less skilled than TD ones, there ought to be a substantial difference between the groups on the social tasks. Instead the result was unexpectedly equal. On the whole, the results from the studies should be seen as valid and reliable and able to generalize to a larger population of AS.

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