# Table of Contents

## 1. Introduction
1.1. Early detection of Autism Spectrum disorders
1.2. Practical manual

## 2. Background
2.1. Introduction
2.2. Signs of ASD in very young children.
   2.2.1. Reciprocal Social Interaction
   2.2.2. Communication
   2.2.3. Rigid and restricted patterns of Behaviour and Interest

## 3. Early Detection
3.1. What is early detection?
3.2. A practical Instrument: Red Flags
   3.2.1. Making use of Red Flags

## 4. Screening
4.1. Administering the ESAT
4.2. Interpretation of the results
   4.2.1. What if parents/carers do not want to collaborate?
4.3. ESAT items
4.4. Video clips

## 5. Diagnostic Assessment
5.1. Introduction
5.2. Assessment in very young children
5.3. How does one evaluate behaviour in very young children?
5.4. Different expressions of autism spectrum disorder in very young children
5.5. Diagnostic procedures in very young children
5.6. The assessment process
   5.6.1. Taking the behavioural history
   5.6.2. Developmental history
   5.6.3. Assessing parents functioning in bringing up their child
   5.6.4. Family history
   5.6.5. Psychiatric examination
   5.6.6. Cognitive assessment
   5.6.7. Physical examination
   5.6.8. Making a diagnosis
   5.6.9. Informing the parents/carers
5.7. Centres for Early Detection in your country

## Acknowledgements

## On the authors

## Addendum 1 Scheme
Preface

The ESAT – Screening of Autism Spectrum at a very young age: a practical manual on early detection, screening and diagnosis is the result of collaboration of Karakter University Cluster at the University Medical Centre St. Radboud in Nijmegen and the department of Child & Adolescent Psychiatry at the University Medical Centre in Utrecht (UMCU)

Karin Beuker MSc, Sharin Mercerea MSc, Iris Oosterling MSc, Kina Potze BSc, Sascha Roos MSc, Nele Schansman MSc, Saskia de Waal MSc, and Tim Woudenberg MSc, contributed to different chapters and video clips in this edition.

The children were all part of the SOS project at the UMCU or the DIANE project at Karakter UCN/UMCN St. Radboud. All parents gave informed consent to permit using the video clips for educational purpose. We are greatly indebted to them and their children for their valuable contribution.

The translations of this manual have been made possible through a grant of the European Union for European network of surveillance on risk factors for autism and cerebral palsy (ENSCAP)
1. Introduction

Autism is a severe neuropsychiatric developmental disorder characterized in all cases by deviances in the development of reciprocal social contact. Autism manifests in an early childhood and persists as impairment throughout adulthood. Autism and all related pervasive developmental disorders, also referred too as autism spectrum disorders (ASD) demonstrate the same underlying three area’s of developmental deviance: impairment in the domain of the development of social reciprocal contact, of the development of verbal and none verbal communication, and in addition, by restricted and stereotype patterns of interest and activities. ASD may manifest in a very different fashion from one individual to another. The level of impairment may vary greatly. Children with a higher cognitive level will display milder signs of ASD than those with concurrent learning disabilities.

ASD presents in children with very different levels of cognitive functioning ranging from severely learning disabled to high functioning. In ASD other disorders are often conjointly present, epilepsy, learning difficulties, anxieties, obsessions and compulsions, depression or mood swings, attentional problem and/or hyperactivity. This comorbid conditions influence in return the autistic symptoms. This implies that no two children with ASD are the same and that ASD may present in very different ways in different individuals.

1.1. Early detection of Autism Spectrum disorders

Despite the fact that ASD is present in most of the children as from birth, in Europe the diagnosis is seldom made before the fourth year of life. Yet early recognition and diagnosis of the condition is crucial; the earlier the diagnosis is made, the earlier intervention and guidance can be started. But accurate signalling, screening and diagnosing ASD in very young children is difficult because of the complex variety of presenting symptoms. To ascertain the diagnosis a thorough knowledge of typical development and of the early signs of ASD is of crucial importance.

The ESAT Screening for ASD in Infants Practical Manual was developed conjointly by Karakter Mental Health Nijmegen and the department of Child & Adolescent Psychiatry of the University Medical Centre in Utrecht. The aim of this collaborative effort was to join forces to bundled all the experience acquired over the past years in screening and diagnosis ASD under the age of 36 months and offer tools and materials to enhance awareness for recognizing early signs of ASD in baby’s, infants and toddlers. The complete ESAT edition has a practical manual as well as a theoretical one. There is also a poster showing the most important features of ASD at very young age the so called Red Flags.

This practical manual provides a through description of the features of ASD in very young children. It thus offers professionals in the frontline of child (health) care such as paediatricians, general practionners, other specialist in the field such as psychologists, speech therapists) very effective kit of tools to identify deviances in the social and emotional development at a very early stage in any case before 36 month of age. Hopefully this will enhance awareness resulting in earlier diagnoses of ASD.
The practical manual sums up the current state of our knowledge with regard to signalling, screening and diagnosing ASD in young children and introduces two instruments one for detecting and the other for screening for ASD. Along with the practical manual comes a DVD with video clips meant to illustrate the kind of behaviours one is looking for. Thus it offers the possibility for professionals working with very young children to train their skills and aptitudes to detect and recognize deviances in behaviour that could be signals of the presence of ASD in a very early stage.

1.2 Practical manual

This manual tells how ASD presents in very young children. Red Flags that signal the possible presence of ASD in these very young children are formulated. If one or more of these Red Flags is present a full assessment of the developmental features of this child is of great importance. The ESAT (Early Screening of Autistic Traits Questionnaire (ESAT Swinkels, Dietz, Van Daalen, Kerkhof, Van Engeland & Buitelaar 2006) is very well suited in this second stage of the assessment. This manual offers a description of this screener and guidelines for administrating and a thorough explanation of the different items. Both the items of the ESAT and the behavioural signs of ASD at very young age are illustrated by the different clips on the DVD. But the manual also provides information on the procedure and the tools and instruments used during the diagnostic workup. A description of the background and history of our knowledge of early signs of ASD, and the psychometric characteristics of the Red Flags and ESAT are given in the Theoretical Manual.

The behavioural features, detecting process, screening and the diagnostic assessment are found in the different following chapters:

- In chapter 2 we will review the behavioural characteristics of ASD at a very young age. As there are to date no biological or genetic markers to identify the disorder, the diagnosis is based on these behavioural features. Video clips illustrate these behaviour characteristics. The typical development will be described in contrast.
- In chapter 3 professionals are offered practical guidelines to detect and recognise behaviours related to the emergence of ASD. We will pay special attention to the Red Flags that can prove helpful in the process.
- In chapter 4 the appraisal of the risks following features detected by the Red Flags in chapter 3 are described. The ESAT as an instrument for further investigation is presented. All the different items will be discussed and illustrated by video clips.
- Finally in chapter 5 the diagnostic assessment procedure will be described as well as the different services to which one might want to refer children for a diagnostic work-up.
2. Background

The two first years of life of a child with autism

As his parents remember Imar had a difficult start. It took weeks before he could drink and swallow properly. Then he only took practically only fluids during his first year because he could not cope with solids (fruit and bread). Imar cried a great lot and was easily upset. His parents were worried and puzzled because they did not understand what was causing all that trouble. Imar ran many colds with otitis media in the process. His parents thought that all his ear problems were to blame for him not starting to talk before he was two years old. In hindsight he was very late at making gestures too. He did not wave to say hello or goodbye. He hardly ever pointed to show or share interests. He does not enjoy being cuddled and preferred to be left on his own. Once he could sit, he was totally absorbed by books that he wanted to browse over and over again. But unlike his sister he showed no interest in “reading books together”. Imar needed no toys to keep him busy. He could spend hours in a row, opening and closing doors. He was remarkably silent.

2.1 Introduction

Many parents/carers, just as Imar’s parents did, were concerned with the development of their child right from the start of their life. “He was so silent and hardly produced any sounds” “she hardly ever reacted to what was going on around her” and “our child was very late at speaking”. These are worries they bring to their paediatrician when consulting for regular check-ups. The concerns are about delays in developing. Along with those given before others would be smiling, laughing, reaching for objects, sitting, crawling, standing up, walking and babbling. For each of these features there is an average age when most children typically reach these milestones in development. Delays may worry parents; these will be the first signs that something could be at hand (Charman & Stone, 2006)

Most of the children with ASD have serious developmental delays between the ages of two to fours years of age. Most of them had been noticed by their parents as soon as their first year of life (Charman & Stone 2006). From different studies it is clear that in 30% of the cases of ASD parents report that their worries started during the first year of life of their child. As many as 80% of the parents were seriously concerned about the development of their child during the two first years of their life (Charwarska, Paul, Klin, Hanningen, Dichtel & Volkmar, 2007).

Many of those concerns are by no means specific for ASD. Most of the parents express worries concerning the motor and language development. Parents are less often concerned about delays in social development. The more specific early signs of ASD are difficult to discern. Parents/carers are thus likely not to recognise them.

It is very difficult to distinguish clearly a general retardation (learning disability) from a specific developmental disorder as ASD at a very young age. Moreover ASD may present along with a generalized delay in development. But ASD and learning disability are clearly different. In learning disabilities the delay spreads out over all domains of development likewise: motor, cognitive, communication and social development are behind at the same degree. There is no reason to suppose that specific signs of delays in social reciprocity as joint attention (pointing, sharing, following others gaze and pointing) and sharing interest are more impaired that other domains. But children with learning disabilities may fail to anticipate in an adequate fashion to social engagement by parents/carers and other adults. This can cause them to become relatively isolated and engage in stereotype activities to temper their inner unrest.
Such behaviour can also occur when children with learning disabilities are over- or under stimulated by their social environment. In clinical practice the distinction between learning disability and ASD may prove difficult. To distinguish them it is important to relate the development of social reciprocity to the general (cognitive) level of development of the child. In children with ASD the social delay will be more marked whereas in children with learning disabilities their social reciprocity will match their cognitive level or be slightly in advance of it.

Likewise the distinction between ASD and a specific developmental disorder of speech and language may be difficult to make in very young children. In the case of specific developmental delay in receptive and expressive language, the disorder is limited to spoken language, but not to the development of non verbal expression and comprehension, like making and understanding gestures, communicating through gestures or the pragmatics of language (imitation of behaviour, understanding others intentions and affective states. But in daily life children with specific language and speech disorders may not react properly to social engagement and it may prove difficult to make a clear-cut distinction between their condition and ASD.

Yet early detection and screening for ASD is of great importance in order to start intervening as soon as possible. When diagnosed in an early stage the developmental gap with typically developing children is still relatively small. Moreover the plasticity of the brain is bigger in very young children than later in life. Nerves cells and brain circuitries may adapt to changes in very young children a capacity that diminishes dramatically as they grow older (Didden & Huskens, 2008). Finally an early detection, screening and diagnosis, may reduce the period of stressful doubts and worries in parents/carers.

2.2 Signs of ASD in very young children.

To be able to detect and diagnose ASD at a very young age, one has to be well aware of the different ways in which the early signs present in daily life. There is a big variation in behavioural expressions. Often times the behaviour in question is not missing but the difference with typical development is quantitative (less often present) if qualitative (“different”). The different expressions of these behaviours will be illustrated in the video clips. They expressions of ASD in very young children will all be in one of the three domains that’s characterizes ASD: reciprocal social interaction, communication and rigid/stereotype patterns of interests and behaviours. For each domain there are two video clips that are introduced in the text. The clips contrast typical and deviant expressions. There is one exception for the rigid/stereotype patterns of interests and behaviour two examples of deviant behaviour will be given. The selected video illustrations come from diagnostic situations and were helpful in making the diagnosis. To get well trained in distinguishing the subtle differences at a very young age, we suggest that you read the text several times and watch the video fragments several times too.
2.2.1 Reciprocal social interaction
At a very young age (below 36 months) limitations in social interactions may manifest in a restricted interest for the social environment and limited back en three (reciprocity) in social interactions. These shows for example in limited engagement in social play as rolling a ball back en three or disinterest in social games like peak a boe. In these games the interaction is the core of the joint pleasure and not the materials in se. typical children love these games and can play them over and over again. But even so children with a mild retardation in development may thoroughly enjoy games like peak a boe or rolling a ball back and forth! A child with ASD will not be inclined to engage in these games, will express limited pleasure and will make little eye contact in the process. When they indeed do enjoy the game (physical sensation) they will laugh in an undirected way, whereas typical and learning disabled children will show like an innate tendency to look at the other to share their pleasure in the common activity.

When ASD children do play, they will not invite others to engage in the game together with them. Neither will they show objects to others. Children with ASD will have a limited rang of facial expressing and make very hardly any gestures. Children with ASD appear to be very undemanding when it comes to playing.

At the end of the first year of life, typical developing children will react very strongly to their parents leaving the room. Most parents anticipate to this fear by letting the children know that they are leaving but will be returning soon. Children with ASD will on the contrary show relatively little to no reaction when their parents leave them. They can stay alone without being alarmed. Their parents know they will not get upset and are not inclined to tell them that they well leave of comfort them in the process.

FRAME:

- **Qualitative impairment restrictions in social and emotional interaction as manifested by**
  - Marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction.
  - Failure to develop peer relationships appropriate to developmental level
  - A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. lack of showing bringing, or pointing out objects of interest)
  - Lack of social empathy.

**VIDEOCLIP 1**

As stated before peak-a-boe is a game that normally appeals to the natural tendency of children to engage in sharing activities, being actively part of a social game and the importance of eye contact.

This video clip shows a child 34 months of age. He grabs the cloth with which the adult wants to engage him in a peak-a-boe game, but he shows not interest what so ever in the other. The boy makes no gaze contact and there is no shared pleasure with the adult. He does not get actively involved in the game and does not make any initiative to encourage the adult to repeat the activity (over and over again). As far as he shows any interest it is more in the materials than in the interaction with the adult (lack of social interest). Though less easy to see, this boy shows very expression in his face. He laughs occasionally when taking the cloth from his head, but it is hard to know if he enjoys it or not.
**VIDEOCLIP 2**

Social interaction is the core pleasure in rolling a ball back and forth. Typical children will enjoy the interplay and react to the actions of the other. A child with ASD will be more focused on the ball itself and only marginally interested in the game and will not pay attention to the facial expressions of the other.

In this video clip the contrast between a child with ASD and a learning disabled child is illustrated by this girl 32 months of age. She is globally retarded what shows in the clip by the fact that she van hardly speak. But on the other hand it is very obvious that she fully engages in and enjoys the interaction with the assessor. She takes initiatives and even engages her mother to join in the fun. She shares by saying “ball”, “just” “mum” and by showing the ball. She laugh well directed to the assessor and towards her mother. There is evident shared joy. The girl makes frequently eye contact and has a vivid facial expression.

2.2.2. Communication

Limitations in the quality of communication in children with ASD manifest itself mainly by the fact that they not or hardly actively use language. Most very young children with ASD have a big delay in language development and do not speak at all. The main difference between children with a language delay with ASD and those without ASD, lays in the fact that children with ASD do not compensate for their lack of spoken language by using gestures or others means of expressing their needs. A child with a specific expressive or receptive language developmental disorder will do so. Typical children actively use gestures to express themselves long before they use spoken language (Fenson, Dale, Reznick, Thal, Bates, Hartun, Pethick & Reilly, 1993) children with ASD thus also show a marked delay in the development of non-verbal communication.

Children with ASD that do develop spoken language, do often not engage in conversations with a back and throe, in other words do not engage in tow way conversations were in turns one reacts to what the other said.. Some children with ASD may use words with no intention to communicate. Others children with ASD will repeat literally words or sentences that they hear (echolalia). Repeating words is a normal phase in mastering spoken language in typically developing children. But they will repeat it in a meaningful and not in a mechanistic way. Sometimes children with ASD may communicate in a very special fashion, namely but making an instrumental use of the other. The ASD child grabs the part of the body (mostly the hand) of the adult to direct it towards the object he wants to get, without making a sound or gaze contact, but only to get hold of what is beyond his reach. A typical child may at times grab your hand, but will do this jointly with gaze contact and words of babbling to underscore his request. In other words a typical child will try and communicate what it wants.

When one addresses a child with ASD, it will often not react. The child does not react when called by its name. This may occur even in the presence of a hypersensitivity to noises. Children with ASD may be extremely sensitive and get extremely upset by noises of a hoover, coming from a radiator, a distant airplane. More details on these hypersensitivities will follow in paragraph 2.2.3.
Inexplicable emotional reaction may also be early symptoms of ASD. Parents/carers will typically report that they do not have an idea as to what makes the child laugh or cry all of a sudden. It will be important to assess whether this stems from the child or reflects a lack of knowledge, experience or sensitivity for signs in a child from the side of the parents. On the other hand many children with ASD will have tremendous difficulties in making clear to their environment what they want of feel.

FRAME:

QUALITATIVE LIMITATIONS I THE DOMAIN FOR COMMUNICATION MAY MANIFEST:

- delay in, or total lack of, the development if spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
- In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others.
- Stereotype and repetitive use of language or idiosyncratic language
- Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.

VIDEOCLIP 3

In this clip a boy aged 33 months shows an instrumental way of communicating. He grabs the hand of an adult he does not know to get him to hand him over what he wants. He makes no usage of verbal or nonverbal communication. He can make eye contact, but does not use it in an integrated fashion to make clear what he wants. There is no back and throe in the communication: for instance the boy does not react to the spoken language of the adult by making noises of gestures.

VIDEOFRAGMENT 4

This girl age 15 months has a very limited vocabulary but can make absolutely clear what she wants. In contrast with the child form clip 3, who is older. In this fragment we can see how she expresses herself, with a few words, but mainly by words (nodding “no” and pointing) a babbling with a variation in the pitch of her voice that in combination with her expressive face makes it absolutely clear what she wants. Her reaction to adult speech is adequate; despite the limited language development there is a clear-cut back and throe in her communication.
2.2.3 RIGIDITY AND STEREOTYPIES IN BEHAVIOUR AND INTEREST

Preoccupations with parts of objects or patterns are the behavioural manifestations in behaviour of the restricted and rigid patterns of behaviour and interest. The restricted patterns show, but an exclusive interest in a particular topic (windmills, washing machines, cars) and when along with this focussed interest, the child does not manifest interest for other toys. Playing in these patterns is an endless repetition of the same behaviour (opening and closing doors) or activities sorting objects by size, shape of colour). From their first birthday onwards typically developing children will start exploring their environing world and play in a varied manner. Children with ASD hardly explore and their play activities are restricted and remain repetitive.

Imaginative as if and symbolic play that normally emerges during the second year of life does not show in ASD children or is ritualistic in a rigid fashion (always the same pattern to which others imperatively should abide).

Many children with ASD hang to sameness and have great difficulties in accepting change. They cling to fix patterns (rituals) and sequences (routines). For example children that will never brush their teeth before taking a shower, or will not start eating unless mother has taken a spoonful. Most infants like routines but bear change, whereas ASD children will get extremely upset if routines are not completed or changed.

Children with ASD may show stereotype motor movements, for example turning around continuously, rocking of head banging. Every two year old child will bang its head when having a temper, occasionally, as they will enjoy spinning around to experience dizziness. But children with ASD will do it by means of autostimulation and by no means as a way of sharing or communicating. The message is not “I want to have it my way” or “look at me, aren’t I clever!”

Many children with ASD will have deviant reactions to sensory stimuli from none at all to extreme. These children will react in a dramatically strong way to noises, light, pain, tickling or will on the contrary not react at all! The opposite may be the case too. For instance some children with ASD will not experience any pain. Many children with ASD do not like to be touched or cuddled. Though these reactions are not specific for ASD, they can be considered as characteristics that occur more often in ASD.

FRAME DSM CRITERIA:

RESTRICTED REPETITIVE PATTERNS OF BEHAVIOUR, INTERESTS AND ACTIVITIES

- Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.
- Apparently inflexible adherence to specific, non-functional routines or rituals
- Stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole body movements)
- Persistent preoccupation with parts of objects
**VIDEO CLIP 5**

In first instance this boy’s (29 month of age) behaviour seems absolutely normal. He exams the wooden blocs very carefully. But then he seems to get hooked into this behaviour; he repeats the same manipulation over and over again. There is no variation in his game. This is by no means a normal explorative way of behaving. A typically developing child would start play and building with the blocs.

**VIDEOCLIP 6**

The boy in the clip is 31 months of age. He seems tremendously absorbed by his activity. His play is stereotype because he keeps on ordering the materials; he puts all the wooden blocs and puzzle elements in a row. A typical child could do the same, but will not always do it with what he is presented with. It is remarkable to see how he gets fascinated by the perspective and looks at it from different angles. Because of the repetitive and rigid pattern, this is a stereotypy. When presented with new materials he does not show any interest. This boy has an uneven profile of skills. As compared to children his age, his visuospatial capacities and fine motor skills are well in advance. But area’s that do not stir the same kind of interest are way behind. From this sample it is clear that it is merely impossible to interact with this boy. He does not share his interest and by no means reacts to being spoken to/ he thus shows limitations in explorative behaviour, variety of play and also in the area of communication.

3. Early Detection

Children may show signs from very early in their life on that can be related to an Autism Spectrum Disorder. This chapter will explain which these signs are by introducing the notion of Red Flags and how they applied in order to detect ASD in very young children.

3.1 What is early detection?

Early detection is the term that refers to the process of identifying children that are at risk for developmental hazards. The aim is to find risk symptoms in children in the community. Detecting a risk factor does not imply jumping to conclusions and making a diagnosis. It could be that the child has an ASD. But even probable is the identification of a language delay problem or a precursor of Attention Deficit Hyperactivity Disorder (ADHD). In many cases it will be a false alarm and no disorder will become apparent. Having one of the early signs only implies that there is an enhanced risk for developing ASD. The second step after detecting is screening to investigate the risk more in detail.

Detecting symptoms that may point out to ASD is complex. Recognizing these early signs is far from easy. The stereotype image of the aloof child with special talents as in the film Rainman hardly fits any kid. ASD mostly presents in a very different fashion. Most problems go unnoticed for a long time or they are not acknowledged as related to ASD. Moreover several studies show that the worries of parents concern problems in the development of their child that are by no means characteristic for ASD. Parents can worry about excessive crying, tantrums or delays in reaching motor en language milestones in development. The latter are signs that might fit a diagnosis ASD, but could also occur within other developmental disorders. Moreover the brackets for reaching developmental milestones is quite broad which implies that sometimes a delay in developing spoken language may merely reflect a familiar
trait of being late at speaking. Problems in the area of social development are far more specific for ASD, but they can go unnoticed because too subtle to be remarked by inexperienced parents (Dietz unpublished). Often times parents will say that they do not had severe worries about the social development because the child (at time) makes gaze contact. But when one looks explicitly into the quantity of eye contact (for example the eye contact is too short or the child does not really look into your eyes) or the qualitative aspects (the child makes eye contact but not at appropriate times in communication) then it clearly appears that there is something wrong with the gaze monitoring.

The clinical diagnosis is often not made before the fifth year of live, whereas the parents have worries as from the first tow years of the life of their child. Luckily parents often do get general help before the diagnosis is made but not specifically for their ASD problems. This guidance is often aimed at helping parents to cope with challenging behaviours (tantrums, feeding and sleeping problems). Many children with language delay do get speech therapy and with motor delays physiotherapy.

But an early detection of developmental problems remains important, because the diagnosis can be made at an earlier stage and ASD appropriate interventions and guidance can be started. It is also important to assess whether more general problems are part or consequence of the ASD diagnosis in order to start an appropriate intervention and in cases where an other developmental disorder is at hand, aimed at helping specifically in those cases too..

3.2 A practical Instrument: Red Flags

In order to provide some help for the complex early detection process and enhance awareness in professionals in the field of care and prevention aimed at very young children to detect early signs of ASD, specific Red Flags were proposed. They were first described by Filipek et al (2000) and have been in use in the United States since then. Infant health care authorities have implemented them in the UK (LeCouteur, 2003). The original set of Red Flags with additional “developmental” characteristics that appeared to be the most powerful indicators in a Dutch study (Dietz et al. 2007) were tested on a Dutch population sample. This has lead to the following list of Red Flags (see frame) with an additional mention of the age at which the child should have reached this developmental milestone. The complete description of the Red Flags is included in the Theoretical Manual.

To provide the professionals that administer the ESAT with clear overview of the Red Flags, these have been illustrated and fitted into a poster. This poster can be hanged on the wall in waiting rooms or professionals offices. The illustrations follow in this chapter.

3.2.1. Making use of Red Flags

The Red Flags are developmental milestones that in the Netherlands are check for in the so-called Van Wiechen- scheme for monitoring development at the local community paediatric services. This scheme is applied in repetitive measures an attended by 98% of the Dutch population (Laurent de Angelo, Brouwers-de Jong, Blijsma-Schlösser, Bulk-Bunschoten, Pauwels & Steinbuch-Lindstra, 2005). In that sense the Red Flags are not additional too what is monitored currently. But they prove helpful for professionals as GP’s that see many of these children but in a less systematic way. When the professional is aware of these Red Flags, he/she can assess them during the consultation with the child and its parent’s carers. They can also be administered as a questionnaire. Even “one” positive Red Flag is a clear-cut criterion to take action promptly. Each child that has at least one positive Red Flag should be invited to participate in an assessment where with the ESAT (chapter 4) one can look into the developmental deviance more in detail.
Any worry or concern expressed by parents, or other carers involved with the child in question, should be taken into consideration and referred to a second stage screenings interview with the ESAT.

FRAME:

**Red Flags**

A child

- does not babble at 12 months
- does show interests in other people at 12 months
- does not react when spoken to at 12 months
- does not make gestures (pointing, waving) at 12 months
- does not make use of words in a functional manner at 18 months
- does not use two-word sentences (no echolalia) at 24 months
- has any loss of language or social skills at any age

For the staging of the screening procedure we refer to addendum 1.

---------------------------------------------------

FOLLOW FIGURES 3.1a to 3.1h where the cartoons illustrate the items of the Red Flags

---------------------------------------------------
4. Screening

Once the risk has been detected in a child, it is important to weigh possible impact of the risk in a quantitative way. The ESAT screenings questionnaire is well suited for this purpose. In this chapter the ESAT is described and all the items are reviewed and illustrated with video clips.

The screenings questionnaire ESAT ( ) was developed at the University Medical Centre in Utrecht. The items were chosen to suit (very young) children with a developmental age up to 36 months. The real age of these children may be higher in those who present with a developmental delay. For a description of the backgrounds and psychometric qualities of this screener we refer to the theoretical manual.

In this chapter the practicalities of administering the ESAT are presented. After a description of the administering procedure, the scoring and interpretation of the results, all the items will be reviewed systematically. The aim of these descriptions is to give a clear idea of which behaviours should be scored. Then follow the texts illustrating the different video clips. Some clips will be useful to illustrate different items as behaviours cannot be seen in isolation. The clips aim at giving a better understanding of what the items refer to. Both the description of the item as the video clip and its description should help the assessor to push the questions to the parents in order to get a reliable scoring on the items. (see next paragraph)... 

4.1 Administering and scoring the ESAT

The ESAT consist out of 14 questions, that relate to the three domains within ASD: impairment in the development of reciprocal social interaction, impairments the development of communication and restricted and stereotype patterns of behaviour. Screening with the ESAT can be performed by a variety of well trained professionals (community workers such as paediatricians, nurses and other professionals within community based Early Intervention Teams, speech therapists, physiotherapists, psychologists and educationalists).

The questions are addressed to the parents/carers. The questions all refer to concretely perceptible behaviours and features. The question is whether this behaviour does or does not occur in the child. In order to ensure reliable answers to the questions it is of importance that the professional administering the questionnaire should be able to provide the parents with a series of examples to make clear which behavioural features are referred too in the question. The administrator will ask for several examples from the parents/carers to ensure whether this behaviour is or is not present in this child. This is called asking in depth. This is only possible when the professional exactly knows what kind of behaviour is relevant for the item. The video clips provided with this manual should help the professional to train himself on the different items. The questionnaire is preferably administered whilst the child itself is present. This enables the professional to witness some of the behaviours he is asking for. These direct observations may weigh in the scoring by the professional. Moreover the behaviours that the child shows (or does not show) may help the professional to question the parents more in depth. Finally the professional will decide, based on questioning and direct observation to score a “yes” (present) or “no” (not present).

After completing the scoring all the negative scores (the “ no[t present] items ) will be summed. The exception to this rule is item 8, where the presence of the behaviour (thus a “yes”) will be taken into account in the addition.
In order to become an adequate and reliable administrator of the ESAT, it is recommended to watch carefully and several times the video-clips both for the Red Flags (including those described in chapter 2).

Often times the items refer to behavioural features that are subtle and not easily perceived. It is therefore of uttermost importance to have a very clear image of meaning of each items in order to question the parents/carers and to pursue questioning in depth.

4.2 Interpretation of the results.

If the sum score on the 14 questions is 3 or higher, the ESAT considers the problems that the child presents with as “screen positive”. Children with a screen positive ESAT score should be considered at high risk for ASD and should be referred for further assessment to a specialized team. A screen positive score means that the there are currently social and communicative developmental issues that should be considered and addressed. Studies confirm the high risk status for ASD in these children. But the ESAT is not a diagnostic tool and does not provide direct evidence for the diagnosis ASD. It could be that other developmental hazards such as specific language- or other developmental problems are at hand. In some cases such delays or deviances may be temporary and will not reflect a lasting developmental problem. The problems may be adaptive or reactive to life events such as a divorce or the birth of a younger sib.

When children receive a score 1 or 2 it is strongly advised to keep a close watch on them and to re-administer the ESAT after six months.

For detailed information on addresses for assessment and diagnosis for ASD in very young children, specific information is provided in chapter 5.

The algorithm for stepwise decision-making form detecting thru screening to assessment is found in addendum 1.

4.2.1 What to do if parents are reluctant to collaborate?

Not all parents/carers will be inclined to go for a full assessment of their infant when it receives a screen positive ESAT score. In our population study in the province of Utrecht (Dietz, Swinkels, Van Daalen, Van Engeland & Buitelaar, 2007) is appeared that quite a substantial percentage of parents/carers were not prepared to follow the advice of referring their child for further assessment (Dietz, 2007) many parents/carers need more time to be able to set this step. It is strongly advised to follow the parents pace and keep in touch with them in the mean time. When the developmental problems of the child become more apparent, a referral can always take place. Many parents/carers will in a later stage, reconsider their reluctance to further investigations and accept a thorough assessment for their child.
4.3. The ESAT items.

1 Showing interest in different kinds of toys

- Is your child interested in different sorts of objects and not for instance mainly in cars or buttons?

Children with ASD show limited interest in exploring different kinds of toys. These children may have a very outspoken preference for some object or toys and show no interest what so ever in “new” toys. NB some children with ASD may have a specific interest in parts of objects like wheels or other revolving objects like a washing machine.

2 Variation in play

- Can your child play with toys in varied ways (not just fiddling, mouthing or dropping them)?

Very young children with ASD may latch on to specific activities and will display far less variety in the playing activities then children their age or learning disabled children unlike item 1 it is not their lack of interest in different kinds of objects of toys, but the varied way in which they do or do not play! In children with ASD this play will most often be restricted and repetitive. Examples of this kind of activities are placing and sorting objects in rows instead of discovering what you can do with them. Some children may have special interests and remarkable dexterity in spinning and twirling objects. Others do not explore nor do they play. They just bring objects to their mouth, smell them or throw them away.

3 Puzzling emotions

- When your child expresses his/her feelings, for instance by crying or smiling, is that mostly on expected and appropriate moments?

By expressing emotions the child communicates with its environment. The emotions expressed by children with ASD are often difficult to understand. They seem to occur without any apparent reason. A child with ASD can suddenly start crying or laughing. Sometimes it is the intensity of the emotions that may puzzle their parents/carers because it seems so disproportionate in relation to the event that triggers it.

4 Reaction to sensory stimuli

- Does your child react in a normal way to sensory stimulation, such as cold, heat, light, sound, pain or ticking?

This item refers to hypo- or hypersensitivities. It may concern a remarkable lack of reaction to cold or heat for instance of a remarkably high threshold to pain. The child may seem deaf because it does not react to loud noises. By the contrary: hypersensitivity may occur too. Some children may get upset by the ticking of a clock, noises from a radiator of a distant baby’s crying. Others will cover their ears as in pain at normal sounds like singing. Other may react very strongly to light or being touched. Some children will display both. For instance there may be a hypersensitivity to noise and hyposensitivity for
cold. In other cases a child will not react to the sound of a radio or TV set nearby, but panic at the noise a distant plane/

5 Facial expressions

- Can you easily tell from the face of the child how he/she feels?

Children with ASD may have poor facial expressivity. It will be very difficult hence to read their emotions form their face. Some look older because of their serious and stern facial expression. In others it is the lack of modulation of their facial expression that is remarkable (for instance a cheerful child that seems to remain cheerful by the facial expression under very different conditions). NB it must be noted that some children with learning disabilities but without ASD may also have display a limited range of facial expressions.

6 Gaze contact

- Is it easy to make eye-contact with your child

Here again a variety of deviances may be perceived: in some cases it is obvious that a child makes no eye contact or even actively avoids doing so. In other cases the deviance is more subtle: the eye contact is * fugace* (quantitative deviance) or limited in quality (for instance the child looks at the other but it is more like staring and looking through the other. There can be deviances in timing and tuning into the listeners needs. For instance some children will fix the other at times, but make no gaze contact when trying to draw attention.

7 Demanding attention

- When your child has been left alone for some time, does he/she try to attract your attention, for instance by crying or calling?

Many parents of children with ASD note that their children demand remarkably little attention and can be (too) easily left alone by themselves. A typical child immediately is aware of the fact that their parent/carer for instance is going to the WC and will need reassurance “daddy won’t be long”. Separation anxiety is a normal feature in infants around from their ninth moth of age on. When after a few months they realize that their parents typically return, they will gradually grow to become less upset when one of their parents leaves them. This phase of “separation-anxiety” is often lacking in children with ASD. Parents report that their child did not or hardly reacted when they went out of sight.

8 Stereotype movements

- Does your child have repetitive movements like rocking, head banging, or spinning objects?

Young children with ASD will often show repetitive, rhythmic, motor movements so called stereotypy’s. Examples are rocking with the body, spinning around, flapping with the arms (when excited), holding spread fingers in front of the eye’s or head banging. These behaviours may occur in typical children too: they may flap their arms and hands
when excited or bang their heads during a temper tantrum. But they will not show these behaviours very often. Or they may do it on purpose as a strong way of communicating their demands. In children with ASD there is not communicative function and the behaviour seems to be repetitive because of the sensation of the movement itself.

9  **Give and Show**

- Does your child, on his/her own accord, ever bring objects over to you or show you something?

Typically developing children show the objects they are playing with to those around them as from one year of age or younger. They like to share their experiences “look mum how beautiful”. Other typical children will enjoy sharing objects or food. Spontaneous showing of objects and giving, passing on things are behaviours that are seldom seen in children with ASD. These children will not ask to pay attention to the tower they have just been building or share their excitement after watching a car passing by.

10 **Showing social interest**

- Does your child show interest in other children or adults?

Though young children tend to play next to each other more than with each other in first instance, it is obvious that typically developing baby’s and toddlers enjoy the company of other children or adults, like to be watched when playing and like to have people in their neighbourhood when they are playing. Somewhat later in their development they are genuinely interested in what others are doing and they are inclined to copy and imitate the behaviour of other children or adults. Young children with ASD are far less interested in others. In a play garden they will be absorbed by their own play activities and will show little to no interest in what they other children are up to. They may ignore approaches by others or be annoyed by them.

11 **Cuddling**

- Does your child like to be cuddled?

Young children with ASD have difficulties with being touched and physical proximity. Some children will resist to being touched or will take no initiative what so ever in engaging in any physical contact with their parents/care givers.

12 **Laughing at…**

- Does your child smile or laugh towards others?

This item refers to social laughing, that is to say pleasure shared with the environment. Young children with ASD are far less directed towards those who are near to them, are little inclined to laugh back when laughed at or to show shared pleasure. Some children with ASD will laugh in themselves or at inanimate objects.
13 **Social play**

- Does your child enjoy games with others, such as peek-a-boo, ride on someone’s knee, or to be swung?

Most of the children with ASD do not like games such as peek-a-boo, games where the fun part is essentially shared pleasure. Child with ASD may enjoy the physical and sensory aspect of being twirled around or hopping on the knees. But the “social” component will be lacking.

14 **Reaction to being spoken to**

- Does your child react when spoken to, for instance, by looking, listening, smiling, speaking or babbling?

Typically developing children as from very young age will react to approaches from their parents/care givers by looking at them, laughing towards them or by making noises. From the age of nine months children will react to the calling of their name. Young children with ASD react less frequently or less explicitly when being spoken to. They will not react to their own name. And many parents will have the impression that they are deaf.

4.4. **Video Clips**

The ESAT items are illustrated by video clips described in the following paragraph. Both typical and deviant related to ASD behavioural features in the course of development are illustrated. As behaviours fitting a screening item are rarely independent, one clip may illustrate several items. For each clip the items are named between brackets. Three items are not included in the clips. These are items 3, 7 and 8. The reason is that these behaviours are not easily seen during an assessment session. For item 8 some of these behaviours occur to seldom to see them during a short period of time.

**VIDEOCLIP 7**

In this clip a boy age 40 months can be seen with a psychologist. The boy seems very interested in the toys, the plasticine with the little candle like sticks. The psychologist tries to engage him in the birthday party fantasy game (sticking the candles in the pie) but the boy clangs to his own activity just poking the stick in the clay (item 2: variation in play activities). He does not show interest in the social aspect of the activity (item 10 social interest; item 13 social plays). His frustration can hardly be read from his face (item 5 facial expressions). Finally he does not make gaze contact (item 6 – gaze contact).

**VIDEOCLIP 8**

In the clip we see the interaction between a sound 20 old toddler and her mother. The girl is strongly directed towards her mother (item 10: social interest). She makes adequate eye contact (item 6 – gaze contract) en spontaneously cuddles her mum (11- cuddling). Finally she reacts correctly when her mother speaks to her (item 14 – reaction on being spoken to).
VIDEOCLIP 9

This boy is 46 months old. His overall functioning is at a lower level (less than 36 months). He does not speak yet. His playing is not varied (item 2: variation in play activities). But he does share his interests and his playing with the environment (item 9: showing and giving). He also makes eye contact in sequence with his mother and the psychologist (item 6 – gaze contact) and laugh well directed (item – twelve ‘laughing at…’). So despite the retardation the social behaviour and skills are well developed. There are no signs of ASD.

VIDEOCLIP 10

This boy (age 26 months) clearly enjoys participating in the assessment session. His face is lively and expressive (item 5 facial expressions). He has a very varied play (item 2) and is interested in different kinds of toys (item 1). But at the same time it is obvious that his does not share his pleasure with his environment (his mother and the assessor); what could have been expected (item 9 Showing and Giving). His does not laugh towards others (item 12). His interest in people around him is restricted (item 10) and he hardly makes any eye contact (item 6). In this boy the deviances seem restricted to the social domain, which is reminiscent of ASD.

VIDEOCLIP 11

Here a 30 month old child is playing with blocks. There seems to be little variation, though the fragment is quite short (item 2 – variation in play). The psychologist interferes on several occasions with the girl’s game. The girl is annoyed. But this emotion cannot be read from her face. She has a neutral facial expression. (Item 5 – facial expression). The girl hardly makes any eye contact, nor with her mother nor with the assessor (item 6 gaze contact). She show no interest for people around her, she seems even to be aversive (item 10 social interest). Finally she does not react when spoken to (item 14). In this girl the signs are mainly in the social domain, making the presence of ASD very likely.

VIDEOCLIP 12

In this clip the assessor presents the child with a toy that makes music, has flickering lights and images. This 24 month old girl seems fascinated and very sensitive to the noise and the lights (item 4 Reaction to sensory stimuli). But it is difficult to see whether she is enjoying it (item 5 facial expressions). Remarkably she does not look at the assessor one single time (item 6 gaze contact). The girl is greatly interested in the toy but ignores the assessor, despite her efforts to engage her by making dancing movements (item 10 showing social interest). Finally she does not react when spoken to (item 14).

VIDEOCLIP 13

This clip shows a typically developing girl (age 15 months) that point to a bird outside to draw her mothers and the psychologist’s attention (item 9 – showing and giving). She has an expressive face and reacts adequately when being spoken to (item 14). She also makes adequate gazes contact (item 6) and share enjoyment by laughing towards the psychologist (item 10 social interest; item 12 – laughing at...).
VIDEOCLIP 14

In this clip it can be seen how the child psychiatrist tries to draw the attention of a boy (31 months) who had a global retardation along but also marked impairment in social reciprocity, communication and restricted interests and behaviours. The boy does not react to his name, neither when the child psychiatrist calls him nor when his father does. (Item 14). He has shows very little interest in the game (item 1) and does not display any variation when playing in fact manipulating toys (item 2). What he does is touching (in this clip the wall and the texture of the material on the chair) what he seems to enjoy (item 4). He has an obvious gaze aversion (item 6) and avoid being touched (item 11). He has a completely neutral facial expression (item 5).

VIDEOCLIP 15

This clip consists of different fragments in which different toys are presented to a child. This boy (15 months of age) shows impairments in the social domain and restricted patterns in his play that make ASD very plausible. The impairments are yet subtle. He does show interest in different kinds of toys (item 1). But the variation in his playing is very limited (item 2). He merely restricts himself to spinning different toys (the phone, the ball, the car …), which he greatly enjoys. He shares his enjoyment and his excitement with people around him (item 9 showing and giving) and names the objects and makes eye contact in the process (item 6). Yet his facial expressions are very limited (item 5).
5. Diagnostic Assessment

5.1 Introduction

The assessment and diagnostic workup in children suspected of having developmental problems in the realm of Autism Spectrum Disorder should be done preferably by specialized professionals in child psychiatric units. The main goals of the diagnostic workup will be to make a diagnosis but also to carefully define the strengths and weaknesses within the developmental profile of the child. In addition risk and protective factors in the rearing environment of the child will need to be identified as they will be important to be taken into account when proposing a guidance schedule for the treatment. Identifying these contours requires a collaborative effort by different professionals specialized in this field of expertise of developmental issues in very young children. This will include child psychiatrists, psychologists, speech therapists, nurses and paediatricians. The assessment of very young children is difficult if one does not have a thorough experience in this field where development may evolve far more rapidly than in older children making definitive statements difficult and requiring more an ongoing diagnostic process. The development will be followed up carefully and that process is of greater predictive value than the assessment of the level and profile of functioning at one point in time.

5.2 Assessment in very young children

In very young children development evolves rapidly, but it is also important to bear in mind that the boundaries of normality are rather broad. Some children will walk alone at twelve months whilst others will start at eighteen months. And yet both reflect normal motor development milestones. Another example could refer to the age at which children get toilet trained. Studies show that the bracket of normality is a broad as a year (Schum et al. 2002). Moreover some behaviours and signs that reflect pathology or retardation at a later age may be perfectly normal in very young children. Toddlers ca very well not play on their own next to other children, whereas from four on children should be expected to be able to play in an interactive way with others. Lacking of this skill may a sign of ASD at elementary school age. But it should always be related to the level of development of the child. The language development may pose similar problems in the diagnostic process. Babies will imitate sounds that they hear from a very young age on. A baby and the caring adult will engage in reciprocal games of imitating sounds. This is an important part of recognizing and mastering sounds in the process of acquiring language. Thus echoing or repeating is a very normal phenomenon in early language acquisition. Children that have difficulties in developing spoken language will have the same behaviour inn that they will imitate and repeat utterances from others. In the latter case the phenomenon will be called “echolalia” and it may be a symptom of language anomalies as seen in ASD. So on symptom may refer to normality or pathology. The behaviour is deviant if a child with a normal cognitive developmental level keeps on repeating utterances of others.

Another difficulty in making a diagnosis ASD in very young children is that the criteria for ASD in the Diagnostic and Statistical Manual of Mental Disorders (DSM IV) and the International Classification of Disorders (ICD 10) are formulated for children in the age 4 to 12, and are often not applicable in very young children. For example the criterion in DSM for reciprocal social interactions refers to skills that normally do not develop before the age of three. In that this item for social contact will not apply for children under the age of three.
Thus looking for signs of ASD in very young children with criteria for older children, is like looking for the young butterfly forgetting that one should try an find a caterpillar.

In sum one can conclude that diagnosing ASD in very young children is difficult both because of the broad boundaries of normality, the fact that behaviours that are pathological later in development may be perfectly normal in very young children and finally that criterion in classification systems poorly apply to very young children.

When one assesses very young children making a diagnosis is just as important as following up the development of the child for an adequate guidance process (Dawson, 2008). Following up the child helps to adapt the interventions to the actual needs of the child and its parents/carers. This will help in enhancing the sound skills in young children and help diminishing the burden of deviances in development. It is of utmost importance to adapt the guidance program continuously to the developing strengths and weaknesses and readapt the developmental profile in the progress. In other words in very young children both the child and the disorder are continuously development and evolution. This is important as one must realize that the plasticity of the brain and thus the ability to induce structural changes through learning is optimal in very young children (Dawson, 2008). In sum “process” assessment in following up the child is important both for affirming or dismissing the diagnosis and adapting the treatment plan to the evolving child and its environment.

5.3 How does one appraise behaviour in very young children?

Behaviour in very young children can, despite all the caveats very well be appraised. This is feasible when one focuses on the frequency, the timing, the context, the severity and the persistence of the occurrence of behavioural features.

Frequency
To assess behaviour in very young children, one shall have to take the frequency of its occurrence into account. Very young children that start exploring materials will do this in different manners for instance by touching and feeling it over and over again, by throwing it, ticking on it or spinning with it. It is remarkable when the child explores the material only in one way. The frequency of that behaviour is then deviant.

Timing
The timing of behaviour may provide important information, eg. the monitoring of gaze contact in children with ASD. Studies show that the in fact look at their parents as often as typically developing children, but at different moments. They do not watch to check if their parents are looking at them (Willemsen-Swinkels et al. 1998).

Context
Another important consideration to assess behaviour is the context in which it is displayed. Toddlers, more than elder children are still very dependant on the context. They will show different behaviour when their parents are around than in presence of strangers. It is important to observe the toddler in different situations, in order to make a sound appraisal of its capacities.

Severity
The severity of the behaviour/symptom should be taken into account too. When toddlers are not able to make their desires clear by saying what they want or not want this can result in a
temper tantrum. In some children these tantrums can take huge proportions with extreme aggression towards themselves or others. The severity of the temper tantrums will be indicative for normality or pathology.

_Persistence_

Finally persistence is a factor in the assessment of behaviour. If a very young child latches on to one specific toy for some time, this is not a matter for concern. When it grows older its interest will broaden and other toys will come in favour. When this does not occur it can be an indication of deviance, for ASD in particular.

5.4 **Assessment of different expressions of autism spectrum disorder in very young children**

In Infants one should not try to discern different forms of autism within the spectrum as they are still difficult to discern and have very little predictive value. De-stability of a diagnosis depends on the likelihood that the outcome of the initial psychiatric assessment will be the same as at follow-up. The ‘official’ classification rules apply to children aged six and more. Studies show that diagnostic shift in type of autism may occur over early development. These are mainly diagnostic changes between autistic disorder and PDD-NOS (Lord et al. 2006; Stone et al. 1999; Eaves & Ho, 2004; Turner et al. 2006; Charman et al., 2006) Sutera et al. 2007). There are not distinct diagnostic rules for children under 6 years of age that enable to make differentiate between autistic disorder or PDD-NOS. Cautiously one should favour the autism spectrum disorder naming in very young children, instead of using more defined terms as autistic disorder, PDD-NOS or Asperger’s. When one labels very young children as having a diagnosis “within” the autism spectrum – ASD – the diagnostic stability is high (Gillberg et al. 1990; Lord et al. 1995; Sigman et al. 1999; Stone et al. 1999; Moore & Goodson, 2003; Eaves & Ho 1999, Charman et al. 2005; Chawarska et al. 2007 and van Daalen et al. 2009). This implies that children that were diagnosed ASD at a very young age, would be re-diagnosed as such at a later age.

5.5 **Assessment procedures in very young children**

The assessment process begins with a diagnostic question. Mostly this will be done by asking for behavioural and developmental problems and teasing out in how much they match with what is known about ASD? The assessment procedure will try and answer this question. The second aim will be to assess the strengths and weaknesses in the child and in the rearing environment. The therapeutic goal will be to provide specific guidance to help parents cope with handicaps in their child given their own possibilities and limitations.

The assessment process has different stages. Firstly information will be retrieved from parents/carers, from the child itself and if possible from third party as childminders in day-care centres etc. In the following paragraphs different aspects of this procedure will be highlighted.
Variations in context and circumstances
It is of great importance to see a very young child in different circumstances, because the presentation of the problems may vary greatly according to the moment in time during the day and will be dependant of the setting in which the child’s behaviour is observed (Klin et al. 2004). This is even more true in children with ASD because to due to their limited adaptive skills, daily functioning will cost them a tremendous amount of energy. It is therefore important to ask parents if the behaviours that are observed during formal assessment are representative for the overall functioning of the child. A home visit is therefore an important addition to observations within a clinical setting. The child will normally perform at its best in a well know and safe environment such as home. A home visit enables to observe the child’s behaviour but will also allow one to see how parents have adapted (often without consciously knowing) to the habits, specific routines and rituals of their child. It may also be important to witness the child’s behaviour in presence of other children of the same age. Thus a visit to the day-care centre or a Kindergarten will prove useful. The advantage of such a visit is that one can see the child functioning within a structured and familiar setting with other infants. One must always bear in mind that interactions between infants are mostly still very limited. These children do not engage in joint interactions or as-if play. But direct observation enables one to see how children make contact, engage in activities with other children or react to social openings by others. One can also observe whether these infant make their wishes and demands clear and if they show some beginnings of joint play: sharing, exchanging and joint activities. Very young children with ASD often do not seem to be aware of the presence of other children, some will avoid any contact, and others may disturb children by touching them of literally crossing through their play. This may lead to discomfort in other children that will in turn avoid children with ASD and stay away from them.

Timing
The time of the day is another important factor. Many infants and toddlers will be the fit in the morning of after their afternoon nap. Be careful not to plan anything at feeding or naptime.

Presence of parents/carers
A third aspect to keep well in mind is that very young children need adults around them in order to function well. They cannot regulate their behaviour by themselves and will need adults to provide them guidance and boundaries. This state of dependence on their parents/carers makes it very important that these should be present during the examination and assessment. In presence of their parents/carers and eventual support, very young children will perform better than if seen alone. When their parents are around infants and toddlers will feel more confident to explore the room. They will also tend to be more talkative when their parents/carers are around than in presence of strangers. Seeing the child together with its parents is important for another reason: it helps to see which skills the parents have, and which competencies they lack in order to cope with the behaviours of their child. Appraising the parent/child interactions is an important part of the diagnostic assessment. But sometimes on the contrary they will show less when they get the chance to just sit on their parent’s lap and do nothing at all. The clinician will need to encourage the parents to stimulate their child to engage in activities. Sometimes, if the child does not get too much upset, it is advisable to see the child on its own (with parents watching the assessment through a two-way mirror or video-connection.)
Structural aspects of the rearing environment and complexity of demands on the child

Young children and in particular very young children with ASD will tend to show very different behaviours according to how much structure they are provided by their environment. Their functioning will also depend on the way demands are formulated and their complexity. Given their strengths and weaknesses each child will need an appropriate amount of structure and an adjustment to its capacities of the demands put on them. It is important to know that infants and toddlers will perform better when seated in a chair than sitting on the floor where they can go in all directions.

5.6 The Diagnostic assessment process

This process has the following stages:
1. history of the concerns and challenging behaviours
2. history of the development of the child: pregnancy, delivery, motor-, speech and language- social emotional development. Feeding history, toilet training, growth, sleep, and medical history.
3. parents’ skills and raring experience
4. family history: genetics, learning problems, life events
5. psychiatric examination of the child
6. assessments of the cognitive level of functioning and every day competencies
7. physical examination
8. diagnosis
9. treatment and guidance advice.

5.6.1 Taking the behavioural history

The clinician needs interview parents/carers to take their history. They will be asked to express their concerns and what they expect from the assessment of their child. It is important to list the concerns of the parents and come back to those in the final advice. A systematic history of complaints, strengths and difficulties can be obtained by gathering information via semi structured questionnaires both from parents and others involved in their child such as minders in a nursery or day-care centre. Both the quantitative and qualitative aspects of behaviours should be appraised. It is important to gather information from different sources as very young children are very dependant of their environment in their functioning. Sometimes it is difficult to weigh information from different sources, especially when the opinions on the behaviour and development of the child diverge. Often differences in view between informants stem from the differences in their abilities to exert influence on the behaviour of the child. But the context in which the informer sees the child plays an important role too (Verhulst 2000).

The behaviour of the child is appraised on basis of the criteria already mentioned before: frequency, timing, context, severity and persistence. As infants and toddlers develop rapidly it is important to repeat assessments in order to get a good estimate of the normal and deviant aspects of the development of the child.

It is in these cases of uttermost importance to look continuously to the balance between the boundaries of normal development and symptoms of psychopathology. Such facts are quantitatively well defined and available in reliable developmental schemes. It is of great importance to compare the developmental status and profile to that of the norm population (Verhulst 2000).
These norm data will help to discern the areas of problematic and deviant functioning. The CBCL 1½-5 (Achenbach 2002) is a questionnaire in which parents or other adults involved can indicate challenging behaviours. The instrument has 99 items referring to challenging behaviours in 9 areas: emotionality, anxiety/depression, somatic complaints, sleeping problems, attentional problems and aggressive behaviour. Moreover the instrument translates into five DSM oriented dimensions: affective problems, anxiety, pervasive development problems, attention deficit/hyperactivity problems and oppositional defiant problems.

5.6.2 Developmental history
Information on the course of the pregnancy and early development can help estimate what is within and beyond the norms for the developmental of an individual child. Complications during pregnancy and during the delivery occur more often in individuals with ASD than in their healthy sibs. But there is not solid proof for a causative relation between these pregnancy and birth hazards on one hand and the development of ASD on the other (Zwaigenbaum et al. 2003). Yet many parents have worries about such a causal relationship and this should be discussed with them thoroughly.

Physical development
Tracing physical developmental milestones is an important aspect of the diagnostic appraisal. Some developments (e.g. toilet training) will be more difficult to reach in children with developmental retardation or deviances. But more important are the motor milestones. Hypo-laxity and coordination problems are often seen in children with ASD they may be slower in their motor development. But there is no hard evidence for a relation between motor milestones delay and ASD (Ozonoff et al. 2008).

Sensory development
Assessing the perceptual organs eyes and ears is an essential part of the psychiatric examination. If information on vision and hearing is unclear, one should ask the parents if they have any doubts on these capacities in their child. If any doubt a medical specialist should assess vision and hearing when appropriate. In general there is no difference with regard to seeing en hearing between children with ASD and typically developing children. But children with ASD when asked to react to a certain sound will need more time to respond than healthy controls. The reason for this delayed reaction is yet unclear (Tharpe et al. 2006). It is also of great importance to ask parents if their child has specific hyper- or hypo sensitivities, as these are often present in ASD and may represent a great burden to the child and the family.

General Health
It is important to investigate co-occurring health problems, especially in those children with a suspicion of ASD in which there is also a global developmental retardation. 10-15% will have a disease with a known association to ASD, which is important to detect because it can influence the prognosis and the genetic counselling. It must be noted that 4-42% of the individuals with ASD will develop epilepsy at some stage (Canitano, et al. 2005). Another reason for a thorough physical investigation is that parents themselves may suspect that some physical disease is involved in the causation of ASD in their children. Discussing these features may help them cope with the sad news of having a child with ASD. Though the publication was withdrawn recently (Lancet Feb 2010) because there is no proof of any relationship between ASD and MMR (Mumps – Measles – Rubella) vaccination there is still a belief that MMR vaccination could in fact be a causal factor in ASD.
But it is a fact that gastro-intestinal problems (reflux, constipation, voluminous stools and tummy ache) are often reported by parents of children with ASD. It is advisable to ask for a comprehensive gastro-intestinal examination by a paediatrician. There is no evidence that the immune system is impaired in ASD en thus no grounds for therapeutic actions on that basis (Steyaert & de la March 2008).

5.6.3 Assessing parents functioning in rearing their child
The upbringin of a child with a handicap demands a great effort from parents and drains their energy. In order to tailor an intervention that meets the parent’s needs, the clinician will have map securely their strong competencies in rearing a child as well as their weaknesses in this regard. The sensitivity and responsiveness of the parents may be an important protective factor for their child. On the contrary parents difficulties in imaging what is going on in their child and restricted capacities of tuning in to it’s needs may be a risk factor.
In nearly 50% of the families with a very young child with a diagnosis ASD, parents will complain about a high level of stress and both fathers and mothers can be depressed (Davis & Carter 2008). Though mothers are more burdened than fathers. Moreover it is important to note the the level of stress reported by parents of children with ASD is much higher than in other development disorders!
Of all the factors that may have a negative impact on the rearing environment, the daily routines of feeding and sleeping are by far the most important. These feeding/eating and sleeping problems are by no means specific too ASD. But they cause a huge amount of stress in parents already severely burdened by other aspects of the rearing of a child with ASD. The feeding and sleeping patterns in children with ASD may thus differ from the norm. studies reveal that in fact very young children with ASD sleep less than typical controls and children with learning disabilities without ASD. Likewise it appears that children with ASD have deviant feeding and eating patterns to their healthy sibs. They are more selective when it comes to their preferences. For all children getting used to new foods e.g. solids is quite an adjustment that should be taken in small steps at a time, but for children with ASD these steps should be even smaller (Martin et al. 2008). Parents/carers who are faced to sleeping problems in their child experience far higher degrees of stress as compared to those who don’t (Goodlin-Jones et al. 2008). The level of stress emergin from eating or sleeping problems it higher in mothers than in fathers. High levels of streotyp behaviours also has a negative impact on the parents. It is remarkable that Afro-Merican parents experience less stress in these circumstancesw than Caucasian. Such differences should be known to workers in primary care because the urge for diagnosis and intervention is strongly related to the rearing related stress as experienced by parents (Bishop et al. 2007).

5.6.4 Family history
Twin- and family studies show that genetic factors play an important role in the causation of an ASD development. The heredibility is currently estimated at 95% (Bailey et al. 1995). This implies that sibs of a child with ASD should be considered at high risk for ASD. It is still unclear how ASD runs in families. The exact mechanism of genetic transmission in of ASD. Is yet unclear. It seems to be a complex multi-level phenomenon. It is clear that language developmental problems are more frequent in families with ASD. This implies that the whole family should be considered with emphasis on adequate languagecentrerd helpp for the whole (extended) family.
It should also be noted that ASD is quite frequent in children with known genetic conditions. These are for example Fragile X, Rett’s disorder, tuberous scleroses are 22q11 deletion-syndrome (Steyaert & de la March 2008). In these conditions ASD often cooccurs with a mental retardation and/or epilepsy.

5.6.5 Psychiatry examination
It is very well possible to make reliable diagnoses of ASD as from the age of two (Gillberg et al. 1990; Lord et al. 1995; Sigman & Ruskin 1999; Stone et al. 1999; Moore & Goodson 2003; Eaves & Ho 2004; Lord 2006; Turner et al. 2006; Sutera et al. 2007; Cox et al. 2007; Chawarska et al. 2005; Van Daalen et al. 2009) (see paragraph 5.1). This examination should be done by clinician with a great deal of experience in working with very young children, especially as the diagnostic rules have been formulated for children above the age of four. This implies that the diagnosis at a younger age depends on the skills of the clinician in translating these criteria to equivalent features in early development.

A important aspect is knowing ASD from comorbid conditions that may blur the clinical picture. Many symptoms as seen in ASD may occur also in developmental conditions without ASD, problems in early attachment, anxiety disorders or specific language developmental disorders.

Standardised instruments for children from age four are currently available: ADOS-G (Autism Diagnostic Observation Schedule-Generic) and the ADI-R (Autism Diagnostic Interview Revised). These have not yet been well validated for younger ages. But a toddler version of the ADOS is currently being validated for infants under the age of 30 months. The ADOS-G is a play and interview schedule that, depending of the developmental age, includes tasks in which social interaction, communication, play and as-if play are elicited. The ADI-R is a semistructured interview with the parents in which the domains of social interaction, communication and play preferences and skills are explored by systematic questioning.

The ADOS takes 30-45 minutes to administer and as much to score. The ADI takes 3 hours and an hour to score. Both instruments have algorithms that have cut-off scores for: - “definitive” ASD; - ASD most likely – no ASD. For both instruments one needs to be specially trained and acknowledged.

5.6.6 Cognitive assessment
The purpose of a cognitive assessment is to carefully map the cognitive strengths and weaknesses in the individual, in order to integrate them in an overall developmental profile. This is of importance as it supports the elaboration of adequate treatment and guidance schemes and the search for school or day-care settings. It also may shed some light on the developmental perspective on the longer run. McGovern and Sigman (2005) found a remarkable stability of cognitive potential from school age through to adulthood. The stability from infancy, toddlerhood into childhood is far less clear and one should be cautious when predicting cognitive outcome based on assessment very early in life. Dietz et al. (2007) found a high correlation between the cognitive level as measured in children with ASD from 2 through 4. But it must be noted that in 30% of the children with ASD a significant cognitive improvement occurred over these two years.
Assessment of cognitive functioning should make use of well validated instruments. These are for instance the *Balley Scale of Infant Development* (BSID-II) and the *Mullen Scales of Early Learning* (MSEL). The BSID-II can be applied in children from 1 to 42 months. The instrument scores on three domains: a mental developmental age, a psychomotor developmental index and a behavioural score. The instrument is well validated and has reliable scores. The MSEL covers multiple domains and is applicable in children between 9 and 68 months of age. There are five domains: ‘visual reception’ (non-verbal visual discrimination, perceptual categorisation, memory), receptive language skills, expressive language, fine and gross motor development. In addition it yields a total ‘mental score’. The instrument is widely used in autism research because of its distinct verbal and performance tasks. This enables to appreciate disharmonic profiles (big differences between verbal and performance levels) as often seen in children with ASD. Sometimes specific assessment of language abilities will be necessary. The Reynell and Peabody are the best validated and internationally recognized instrument. The Reynell measures language comprehension from 18m months of age on and the Peabody measures language production from 18 months on. It is well established that the absence of spoken language at age 5-6 predicts a bad outcome in terms of functioning at later age. The limitations that children with ASD show in day to day functioning can be assessed by measuring there adaptive functioning with the Vineland screener 0-6 (Paul et al. 2004). The instrument has 72 items spread over 4 domains: communication, social skills, coping- and motor-skills. It takes parents about 20’ to fill in te questionnaire, that otherwise can also be used as a semi structured interview.

5.6.7 Physical examination
The physical examination of children with ASD is important in order to establish or rule out known chromosomal or other diseases that are known to be associated with or could have caused ASD. Dismorphic signs (physical signs related to developmental anomalies and chromosomal disorders), skin abnormalities (as a symptom of an underlying condition) and neurological disorders (Johnson & Myers, 2007). This enables to establish if it is only ASD or also an other disease. This is important. In so syndromes ASD may be associated with hart diseases that should be taken into account. In ASD a blood test should be done to establish the caryotyp, and rule out for instance Fragile-X and collecting DNA to controle for abnormal genes or mutations. The usefulness of routine neuroimaging or an EEG is questioned. In none of the current practice parameters is it included as necessary. In the case of a second disorder or a mental retardation these extra examinations should be considered to establish the nature of the second developmental hazards. If the medical history shows any indications for underlying medical conditions a thorough genetic and a metabolic screening should added to the examination scheme. The causal relationship is often unclear: did the other condition cause autism or is it just an often co-occurring condition. (Johnson & Myers, 2007).
In very young children, if any doubt, a hearing test should be performed to exclude deafness.

5.6.8 Making a diagnosis
A classification in one of the ASD categories offers little directions for treatment and guidance. The goal of the assessment will be to make a real dia-gnostic appraisal that will serve as basis for the intervention and guidance scheme. All aspects of psychiatric, physical, socio-emotional, cognitive and adaptive aptitudes in their stragths and weaknesses should be well mapped in the context of the family circumstances parents and sibs all included. An integration of all these facts will enable to tailor a treatment and guidance program adjusted to the individual needs.
5.6.9 Informing the parents/carers
THIS PARAGRAPH WILL HAVE TO BE FILLED IN, IN A DIFFERENT WAY ACCORDING TO THE LOCAL SITUATION IN EACH COUNTRY

5.7 Centres voor Early Detection in your country
THIS PARAGRAPH WILL HAVE TO BE FILLED IN, IN A DIFFERENT WAY ACCORDING TO THE LOCAL SITUATION IN EACH COUNTRY