

*This article appeared in the Journal of the Royal Society of Medicine, 2000, 93, 521-525.*

## **The early identification of autism: the Checklist for Autism in Toddlers (CHAT)**

Simon Baron-Cohen+, Sally Wheelwright+, Antony Cox\*, Gillian Baird\*,  
Tony Charman@, John Swettenham\*\*, Auriol Drew\*, and Peter Doehring#.

*\*Newcomen Centre, UMDS, Guy's Hospital,  
St. Thomas Street, London SE1 9RT, UK.*

*+ University of Cambridge, Departments of Experimental Psychology and  
Psychiatry,  
Downing Street, Cambridge, CB2 3EB, UK.*

*@ Behavioural Sciences Unit, Institute of Child Health, London University,  
30 Guilford Street, London WC1N 1EH, UK.*

*\*\* Department of Human Communication and Science, University College London,  
Chandler House, 2 Wakefield Street, London, WC1N 1PG, UK.*

*#Director, Delaware Autistic Program,  
144 Brennan Drive, Newark DE 19713, USA.*

### **Acknowledgements**

We are grateful to the MRC for support for this work through 3 successive project grants to SBC, AC, and GB. Carol Brayne gave us valuable feedback on an earlier draft of this paper.

The **C**hecklist for Autism in **T**oddlers (CHAT) is a screening instrument which identifies children aged 18 months who are at risk for autism. This article explains how the CHAT was developed, how the CHAT should be used, and provides a brief introduction to autism.

### **What is autism?**

Autism, first described by Kanner in 1943 (Kanner, 1943), is one of a family of Pervasive Developmental Disorders (APA, 1994). It is considered to be the most severe childhood neuropsychiatric condition and is characterised by a 'triad' of impairments in socialisation, communication and flexible behaviour. The exact cause of autism remains unclear, though family and twin studies suggest a genetic basis (Bailey et al., 1995; Folstein & Rutter, 1977; Folstein & Rutter, 1988). Molecular genetic studies are underway (Bailey, Bolton & Rutter, 1998). Neural abnormality is evident in a number of different brain regions, including the medial prefrontal cortex (Happé et al., 1996) and the amygdala (Abell et al., 1999; Baron-Cohen et al., 1999; Bauman & Kemper, 1988). It occurs at a rate of about 1 per 1000 (Wing & Gould, 1979). It is widely accepted that there is a spectrum of autistic conditions. Classic autism lies at the extreme of this spectrum. In DSM-IV this is referred to as Autistic Disorder, and in ICD-10 as Childhood Autism. To receive this diagnosis, the onset of the difficulties in social interaction, communication, and flexible behaviour must be before the age of three years. Atypical autism or Pervasive Developmental Disorder not otherwise specified (PDD-NOS) also lie on the autistic spectrum, but children with these conditions do not meet criteria for autism because of late age of onset, atypical symptoms, symptoms which are not very severe, or all of these. Asperger

Syndrome (AS) is thought to be another condition on the autistic spectrum. Individuals with Asperger Syndrome have the social interaction difficulties and restricted patterns of behaviour and interests, but have a normal IQ and no general delay in language. A final subtype are individuals with High Functioning Autism (HFA), who are diagnosed when all the signs of AS are present, but where the child had a history of language delay. Here, language delay is defined as not using single words by 2 years old, or phrase speech by 3 years old.

### **Late detection and the importance of early detection**

Until recently, autism was rarely detected before the age of 3 years. This is not surprising as autism is a relatively uncommon condition with subtle symptoms. In addition, no specialized screening tool has existed, most primary health care professionals receive limited training in the detection of autism in toddlers, and may not have a link to specialist diagnostic clinics. However, the earlier a diagnosis can be made, the earlier intervention can be implemented and family stress reduced, and intervention has been shown to improve outcome (Lovaas & Smith, 1988). In addition, early professional recognition of parental concerns may prevent secondary difficulties developing. The problem is to determine what counts as a cost-effective method of detecting the early signs of this condition.

### **Which behaviours might be important?**

Parents of children with autism often report that they first suspected that their child was not developing normally around the age of 18 months (Wing, 1997). At this age,

there are certain behaviours which are present in the normally developing child which researchers have found to be lacking or limited in older children with autism. Two of these are *joint attention* (Baron-Cohen, 1989; Sigman, Mundy, Ungerer & Sherman, 1986) and pretend play (Baron-Cohen, 1987; Wing, Gould, Yeates & Brierley, 1977). Joint attention refers to the ability to respond or initiate a shared focus of attention with another person via pointing, showing or gaze monitoring (e.g. glancing back and forth between an adult's face and an object of interest or an event) (Bruner, 1983). Joint attention allows children to learn through others - both learning what words refer to (Baldwin, 1995; Tomasello & Barton, 1994), and what to pay attention to in the environment ('social referencing' (Feinman, 1982)). Joint attention is seen as the earliest expression of the infant's 'mind-reading' capacity, in that the child shows a sensitivity to what another person might be interested in or attending to (Baron-Cohen, 1991). Pointing to share interest (or declarative pointing) can be distinguished from a simpler form of pointing (pointing to request, or imperative pointing). This distinction comes from child language research (Bates, Benigni, Bretherton, Camaioni & Volterra, 1979). It is the declarative form which is of particular importance simply because in this type of pointing mind-reading is the driving force ('Look at that! Do you see what I see?'), whereas in imperative pointing this may not be required ('I want that! Get me that!').

Pretend play is a second behaviour to be distinguished. It involves the attribution of imaginary features to people, objects or events (Leslie, 1987). Some theorists view it as signalling the emergence of symbolic ability (Piaget, 1962) as well as mind-reading. Pretence is symbolic in that one object is treated as if it represents something different, and it involves mind-reading by virtue of requiring the child to appreciate

that the person pretending (oneself or another person) is imagining something in their mind. Generally, pretend play is distinguished from simpler forms of play (functional, where the child uses objects appropriately, and sensorimotor, where the child just explores objects for their physical qualities).

### **The CHAT**

The **C**hecklist for **A**utism in **T**oddlers (CHAT) is a screening instrument that was devised to test the prediction that those children not exhibiting joint attention and pretend play by the age of 18 months will be at risk for receiving a later diagnosis of autism. The CHAT is shown in Figure 1. The CHAT takes just 5-10 minutes to administer and is simple to score. The order of the questions avoids a YES/NO bias. The nine questions in section A are answered by the parent whilst the Health Visitor or General Practitioner completes the five items in section B. There are five 'key items' and these are concerned with joint attention and pretend play. The key items in section B are included in order to validate (by cross-checking) the parents' answers to the key items in section A. The remainder ('non-key') items provide additional information so as to distinguish an autism-specific profile from one of more global developmental delay (see Box 1). The non-key items also provide opportunity for all parents to answer 'yes' to some questions.

insert Figure 1 and Box 1 here

Those children who fail all five key items (A5, A7, Bii, Biii, and Biv) are predicted to be at the greatest risk for autism. In Box 2, we call this the *high risk for autism group*. Children who fail both items measuring protodeclarative pointing, but are not in the high risk for autism group, are predicted to be in *the medium risk for autism group*. Children who do not fit either of these profiles are in the *low risk for autism group*.

insert Box 2 here

### **High-risk (sibling) study**

Our first study tested the effectiveness of the CHAT as a screening instrument in a high-risk sample (Baron-Cohen, Allen & Gillberg, 1992). We studied a group of 50 unselected 18 month olds (Group A) and a group of forty-one 18 month old siblings of children with autism (Group B). The sibling group was selected because they have a raised genetic risk for autism compared to individuals in the general population. Even if we take the most generous estimate of the prevalence of autism spectrum conditions in the general population - 0.34% (Ehlers & Gillberg, 1993) - this is still at least 10 times less than the recurrence risk rate among siblings of children with autism (3%) (Folstein & Rutter, 1977). So the likelihood of finding cases of undiagnosed autism in the sibling group was much higher than in the control group.

The toddlers in both groups were assessed using the CHAT. None of the children in Group A failed all 5 key items whilst four of the children in Group B failed all 5 key

items. A year later, when the children were 30 months old, a follow-up was carried out. None of the children in Group A had autism. The four children in Group B, who had failed the five key items, were diagnosed with autism. This strongly confirmed the prediction that absence of joint attention and pretend play at 18 months of age is a marker that a child is highly likely to go on to receive a diagnosis of autism.

### **Population screening study**

After the preliminary success of the CHAT in detecting children at risk for autism in the sibling group, a more stringent test of the CHAT was set up in a population screening study (Baron-Cohen et al., 1996). 16,235 children aged 18 months were screened with the CHAT from April 1992 to April 1993. These were all children born in the South Thames Region of the UK. Following this first administration of the CHAT, 38 children matched the high risk for autism profile, 369 the medium risk profile with the remainder fitting the low risk profile according to the criteria described in Box 2 above. One month later, all 38 of the high risk for autism group were re-screened and 12 continued to meet the profile. Limited resources meant that only about half of the medium risk group could be re-screened. 22 met the criteria on the second CHAT, two of whom did not continue to participate in the project. 16 children were selected at random from the low risk group to receive a second CHAT and continued to meet his profile. Thus 12 children in the high risk for autism group, 20 children in the medium risk for autism group and 16 children in the low risk for autism group were assessed clinically at 20 months and 42 months. The diagnoses made at 20 months of age were considered to be provisional since this is earlier than the age at which children are usually seen for diagnostic assessment and there is little

or no evidence about the accuracy and stability of childhood autism and PDD diagnoses made in infancy. Confirmatory diagnoses were made at the 42 month clinical assessment. On the whole, we were able to diagnose children with childhood autism reasonably accurately at 20 months of age, in that most were thought to have either autism or PDD at that time point.

By 42 months, 10 of the 12 children in the high risk for autism group had received a diagnosis on the autistic spectrum. The eleventh child was clinically normal and the twelfth child had language delay. In the medium risk for autism group, half the children were diagnosed with autism spectrum conditions (Childhood Autism, Asperger Syndrome, or PDD), two received no diagnosis and the rest had language or learning difficulties. In the low risk for autism group, although 1 child was diagnosed with language delay, the other 15 were normal. Box 3 gives a summary of how the diagnoses in each group changed between 20 months and 42 months. Full details of diagnostic methods can be found elsewhere (Cox et al., 1999).

insert Box 3 here

### **Key issues in any screening program**

It is useful to summarise the key issues in all screening. The following is based on the standard account (Hennekens & Buring, 1987). There are standard criteria for whether it is even worth screening for a disease: To be appropriate for screening, a

disease should meet the following criteria: (1) It should be serious; (2) treatment given early (before symptoms are fully developed) should be more beneficial (in terms of reducing morbidity or mortality) than treatment given later; and (3) the prevalence of the disease should be high among the population screened. Autism meets all three of these criteria in that (a) it is considered to be the most serious of all childhood psychiatric conditions; (b) early intervention improves prognosis; and (c) the prevalence of the spectrum of autistic conditions is high (around 1 in 300). For a screening program to be successful, a suitable screening test must be available. A screening test should ideally have three characteristics: it should be (i) inexpensive; (ii) easy to administer; and (iii) impose minimal discomfort on the patients. The CHAT meets all three of these criteria.

In addition, the results of a screening test must be valid, reliable, and reproducible. Sensitivity and specificity are two measures of the validity of a screening test. *Sensitivity* is defined as the probability of being test positive and truly having the condition. As the sensitivity of a test increases, the number of people with the condition who are missed by being incorrectly classified as test-negative (false negatives) will decrease. *Specificity* is defined as the probability of being screen negative and truly not having the condition. Obviously, it is desirable to have a screening test that is both highly sensitive and highly specific. Usually that it is not possible, and there is a trade-off between the sensitivity and specificity of a given screening test. This trade-off is due to the fact that for many clinical tests, there are some people who are clearly normal, some clearly abnormal, and some who fall into the grey zone between the two. Regarding the number of cases detected by a

screening program, one measure that is commonly considered is the predictive value of the screening test. Predictive value measures whether or not an individual actually has the condition, given the results of the screening test. Predictive value positive ( $PV^+$ ) is the probability that a person actually has the disease given that he or she tests positive. Predictive value negative ( $PV^-$ ) is the probability that an individual is truly disease-free given a negative screening test.

### **So is the CHAT a good screening instrument?**

The CHAT has excellent specificity, low sensitivity, and good predictive value positive. For a condition of this kind, these are acceptable properties of the CHAT. Table 1 shows how many cases of autism alone in the high-risk group were identified and missed in the six years following administration of the CHAT at 18 months. A series of follow-up screening and surveillance procedures were conducted with the aim of identifying all the children from the population with an autism spectrum condition, so as to test the properties of the CHAT in terms of identifying false negatives among other autism spectrum subgroups. Using these methods, a total of 50 children (47 boys, 3 girls) were found who met ICD-10 criteria for childhood autism, and 44 children (36 boys, 8 girls) with other pervasive developmental disorders were also identified. Using the two stage administration of the CHAT, a grand total of 74 children who went on to receive some sort of autism spectrum diagnosis were not identified as being at risk. The sensitivity, specificity, positive predictive value and negative predictive value of the CHAT for all PDDs are shown in Box 4. A comprehensive examination of these data is presented in a six year follow-up paper (Baird et al., submitted).

insert Box 4 and Table 1 here

Just as for autism more narrowly, it is clear that for all PDD's the CHAT also has excellent specificity, whilst the sensitivity is not as impressive. In other words, consistently failing the CHAT on two administrations means that it is highly likely that a child will go on to receive a diagnosis on the autism spectrum. Although with a condition like autism spectrum, having a high false negative rate is not a serious problem (because it is not life-threatening, etc.) it would be good to understand why the rate of false negatives is so high. It may be because some parents are understandably answering questions in Section A in such a way as to put their child in the best possible light ("Yes, of course he points and pretends!"). Since to 'fail' on the CHAT a child needs to fail on both Sections A and B, our team did not look closely at children who only failed on Section B. A second possible reason for the high rate of false negatives is that to fail on the CHAT a child must have *never* produced the behaviour ("Has your child ever pointed/pretended?"). This is clearly only going to pick up the severe or extreme cases and would miss the milder cases who may simply show a reduced rate of pointing or pretending, rather than a complete absence of this. A third reason which could lead to a false negative is if a child had "late onset" autism (Volkmar & Cohen, 1989).

### **Who should use the CHAT and when?**

The CHAT is designed to be administered by any primary health care workers or clinicians in children's services. As a screening tool, it is convenient to administer at

the 18 month developmental check up. Administration of the CHAT to children younger than 18 months is not recommended because of the increased risk of false positives (i.e. identifying children at risk for developmental problems who do not go on to receive a diagnosis). Administration of the CHAT to children older than 18 months is possible, since if a child is still showing a high-risk profile at this age, this is very likely to be a sign of an autism-spectrum condition. Some regions only screen at 24 months, hence us considering this possibility. However, we do not yet know of any data on the use of the CHAT at this age, and suspect that the false negative rate will also be high.

### **What happens if a child fails the CHAT?**

In the population screening study (Baron-Cohen et al., 1996), the first CHAT was administered in the routine 18 month old check-up. Those children who failed this CHAT were re-screened approximately one month later with the same questionnaire. As with any screening, a second CHAT is advisable so as to check that a 'fail' on a key item occurs for valid reasons. Thus, a child might fail on the first administration of the CHAT simply because they are slightly delayed or because of transient factors ('a bad day'). Any child failing the CHAT for a second time should however be referred to a specialist clinic for diagnosis. This underlines that the CHAT itself is not a diagnostic tool. It is important to note that more than a half of children who fail on the first administration of the CHAT lose their risk status following the second CHAT; and the risk group a child is assigned to does not represent a statement of diagnosis.

## Summary

The CHAT is primarily a screening tool for clinical use. It has a low false positive rate but a high false negative rate. In other words, if a child is identified by the CHAT as being at risk for receiving a diagnosis on the autistic spectrum, they are likely to receive one. However, many children will go on to receive a diagnosis who were not identified by the CHAT. If a child meets criteria for the high-risk group, they will almost certainly have an autism or PDD diagnosis. If they meet the criteria for the medium risk group, about half of these will have a diagnosis of autism or PDD, whilst most of the others will have other developmental delay conditions. As far as we know, apart from the CHAT, there is currently no other screening instrument available which has been fully evaluated in this way and which has been demonstrated to be able to identify toddlers who are at risk for autism spectrum conditions. The CHAT is easy and convenient to use and the low false positive rate means that few parents will be unnecessarily alarmed. The CHAT is therefore a very useful clinical tool, especially given the demonstrated effectiveness of early intervention (Lovaas, 1993).

**Figure 1: THE CHAT**

*To be used by GPs or Health Visitors during the 18 month developmental check-up.*

Child's name:..... Date of birth:..... Age:.....

Child's address:..... Phone number: .....

**SECTION A: ASK PARENT:**

- |                                                                                                                         |     |    |
|-------------------------------------------------------------------------------------------------------------------------|-----|----|
| 1. Does your child enjoy being swung, bounced on your knee, etc.?                                                       | YES | NO |
| 2. Does your child take an interest in other children?                                                                  | YES | NO |
| 3. Does your child like climbing on things, such as up stairs?                                                          | YES | NO |
| 4. Does your child enjoy playing peek-a-boo/hide-and-seek?                                                              | YES | NO |
| 5. Does your child ever PRETEND, for example, to make a cup of tea using a toy cup and teapot, or pretend other things? | YES | NO |
| 6. Does your child ever use his/her index finger to point, to ASK for something?                                        | YES | NO |
| 7. Does your child ever use his/her index finger to point, to indicate INTEREST in something?                           | YES | NO |
| 8. Can your child play properly with small toys (e.g. cars or bricks) without just mouthing, fiddling or dropping them? | YES | NO |
| 9. Does your child ever bring objects over to you (parent) to SHOW you something?                                       | YES | NO |

**SECTION B: GP OR HV OBSERVATION:**

- |                                                                                                                                                                                                            |     |           |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|-----------|
| i. During the appointment, has the child made eye contact with you?                                                                                                                                        | YES | NO        |
| ii. Get child's attention, then point across the room at an interesting object and say "Oh look! There's a (name of toy)!" Watch child's face. Does the child look across to see what you are pointing at? | YES | NO*       |
| iii. Get the child's attention, then give child a miniature toy cup and teapot and say "Can you make a cup of tea?" Does the child pretend to pour out tea, drink it, etc.?                                | YES | NO**      |
| iv. Say to the child "Where's the light?", or "Show me the light". Does the child POINT with his/her index finger at the light?                                                                            | YES | NO**<br>* |
| v. Can the child build a tower of bricks? (If so how many?)<br>(Number of bricks:.....)                                                                                                                    | YES | NO        |

\* (To record YES on this item, ensure the child has not simply looked at your hand, but has actually looked at the object you are pointing at.)

\*\* (If you can elicit an example of pretending in some other game, score a YES on this item.)

\*\*\* (Repeat this with “Where’s the teddy?” or some other unreachable object, if child does not understand the word “light”. To record YES on this item, the child must have looked up at your face around the time of pointing.)

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**Box 1**

<b>CHAT Key Items</b>	<b>CHAT Non-key Items</b>
<b>Section A</b>	<b>Section A</b>
A5: Pretend play	A1: Rough and tumble play
A7: Protodeclarative pointing	A2: Social interest
	A3: Motor development
	A4: Social play
	A6: Protoimperative pointing
	A8: Functional play
	A9: Showing
<b>Section B</b>	<b>Section B</b>
Bii: Following a point	Bi: Eye contact
Biii: Pretending	Bv: Tower of bricks
Biv: Producing a point	

**Box 2**

**High risk for autism group:**

fail A5, A7, Bii, Biii, Biv

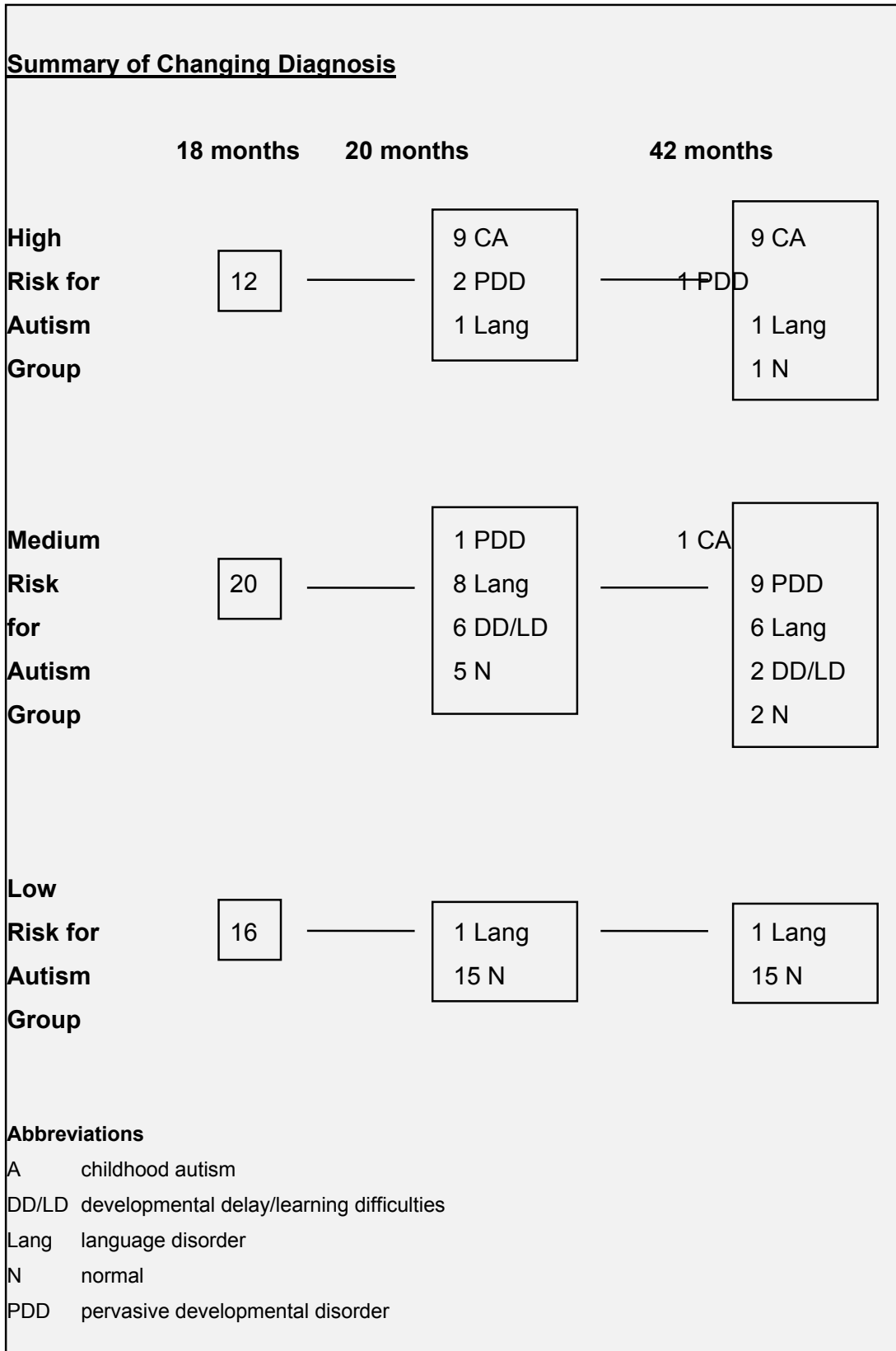
**Medium risk for autism group:**

fail A7, Biv (but not in maximum risk group)

**Low risk for autism group:**

not in other two risk groups

**Box 3**



**Box 4**

For all PDDs and combining the medium & high risk groups,

**Sensitivity:**                      20/94 (21.3%)

**Specificity:**                      16127/16141 (99.9%)

**Positive predictive value:**      20/34 (58.8%)

**Table 1: Data from the CHAT population study (for childhood autism in the high risk group only)**

Results of screening test	Disease status		Total
	Positive	Negative	
Positive	9	3	12
Negative	41	16 182	16 223
Total	50	16 185	16 235

$$\text{Sensitivity} = \frac{9}{50} = 18\%$$

$$\text{Specificity} = \frac{16\ 182}{16\ 185} = 100\%$$

$$\text{PV}^+ = \frac{9}{12} = 75\%$$

$$\text{PV}^- = \frac{16\ 182}{16\ 223} = 99.7\%$$

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