# Screening for Autism in Toddlers: A Revised Measure

**By Carrie Allison & Simon Baron-Cohen**

Autism is a lifelong Pervasive Developmental Disorder (PDD) that is characterized by qualitative impairments in social interaction and communication, along with repetitive and stereotyped behaviors and/or interests. Autism is one of several conditions that represent variations in the manifestation of impairments, including Asperger Syndrome (AS), atypical autism and PDD not otherwise specified (PDD-NOS). Autism is behaviorally defined, although the etiology may be genetic, neurobiological (Bailey et al., 1995; Bolton et al., 1994), and/or neuroanatomical (e.g., Courchesne, Carper & Akshoomoff, 2003) in origin. There is no clear unifying pathology at the genetic level (Geschwind, 2008). The prevalence of autism has been estimated to be as high as affecting 116 per 10,000 individuals, or 1 in 86 (Baird et al., 2006).

Traditionally, autism was conceptualized as a distinct categorical condition defined by behavioral impairments. Unlike other developmental conditions such as Down syndrome where there is a clear genetic etiology, there is no biological marker that determines the presence of autism. Increasingly, autistic features have been proposed to be on a continuum (Baron-Cohen, Wheelwright, Skinner, Martin & Clubley, 2001; Constantino & Todd, 2003; Wing, 1988), with autism representing the upper extreme of a constellation of traits that may be continuously distributed. This has shifted thinking about autism away from a discrete categorical approach, towards a more dimensional and quantitative approach.

The diagnosis of autism is often delayed because it can be difficult to detect in very young children. Parents often raise concerns about their child by about 18 months (Wing, 1997) but there is usually a significant delay between the point of first concern and an eventual diagnosis. In a large survey of parents of children with a diagnosis of an autism spectrum condition, Howlin & Asgharian (1999) found that abnormal social development was most commonly reported as the main area of concern. In parents of children with autism, this concern was usually noted by 18 months, but later for parents of children with AS (a milder form of autism) - at around 30 months. In a UK longitudinal study, the average age at diagnosis ranged from 45 months in children whose diagnosis was autism, to 116 months in children with a diagnosis of Asperger Syndrome (Williams, Thomas, Sidebotham & Emond, 2008).

The benefits of early detection and diagnosis of autism could be several. First, early detection may allow the child to benefit from the implementation of specific interventions, leading to a better overall outcome for the child (Harris & Handleman, 2000). Evidence that demonstrates that early (versus late) intervention improves outcome is currently lacking, although Lord, Wagner, Rogers, Szatmari, Aman, Charman et al (2005) reports that studies do exist which show significant improvements in outcome for children with autism if intervention starts early (McEachin, Smith & Lovaas, 1993; National Research Council, 2001; Sheinkopf & Siegel, 1998).

**Autism Research Centre**
**Cambridge University**

The ARC at Cambridge University collaborates intensively with outside researchers. As part of their research various tests have been devised. Some of these tests are made available for download.

Tests can be downloaded if they are used for genuine research purposes, and due acknowledgement of ARC as the source is given.

Please visit the following website for further information:
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Lower functioning children may respond better and make measurable gains in IQ if intervention is implemented before the age of four. Second, early detection is important for parents so they can avoid lengthy delays between initial concerns and eventual diagnosis. This may allow them to start learning to manage their child's often difficult behavior. The stress that is sometimes involved in having a child with autism can have consequences for other family members so the sooner the difficulties are recognized, the better (Hastings et al., 2005). Third, early diagnosis may lead to the prevention of secondary difficulties associated with autism, such as anxiety (Tonge, Brereton, Gray & Einfield, 1999), depression, or the prevention of bullying (Howlin, 2000). Fourth, **in the UK** the economic impact of individuals with autism has been estimated to be high. For children, **the aggregate national costs of supporting children with autism are estimated to be £2.7 billion each year, and for adults this amounts to £25 billion each year.** For both adults and children, the majority of this cost is due to services required for support (e.g., residential care for very low functioning individuals) (Knapp, Romeo & Beecham, 2007). It is hoped that earlier diagnosis will allow for earlier implementation of interventions. In turn, this may lead to reduced impairment and ultimately reduce the economic consequences, nationally.

The many benefits to early diagnosis provide the motivation to attempt to improve on current identification and diagnostic practice through screening for autism, with the ultimate aim of leading to earlier prognostic benefit. It is important therefore to identify individuals with autism as soon as possible in order to maximize the support to both the child and their family. In the UK, there is no standardized routine developmental screening for autism (Mawle & Griffiths, 2005) despite a wealth of available screening tools. In contrast to the UK policy, the American Academy of Pediatrics (Council on Children With Disabilities, 2006) recommends that all children receive screening for autism at 18 and 30 months. In the US, there is clearly a different perception about the potential benefits of early detection of autism.

**Attempts to screen children as early as 18 months of age for autism have provided mixed results.** The first attempt took place in the early 1990's in the United Kingdom by Simon Baron-Cohen and colleagues. This landmark study shaped research into screening for autism. The authors developed a measure called the Checklist for Autism in Toddlers (CHAT). The CHAT is a combined parent-report checklist, with a Health Visitor (HV) observation section. This section provides an opportunity for the health professional to rate the child's behavior according to what s/he observes during the appointment. Behaviors that were considered important in the etiology of autism provided the basis for the CHAT items. These included **joint attention, pretend play, social play, social interest, and imitation.** Initially, the CHAT was tested on a group of 41 children at high-risk for autism since they already had a sibling with autism. Results indicated that all those children identified to be at risk at 18 months on the CHAT received an autism diagnosis at follow-up (Baron-Cohen, Allen & Gillberg, 1992). This led to a large scale prospective screening study (Baron-Cohen et al., 1996) whereby over 16,000 children were administered the CHAT at 18 months. At follow-up six years later, it was found that when the CHAT did identify a child to be at risk for autism, it was very accurate in doing so (Baird et al., 2000). In research terms, the specificity was very high, at 98%. **However, the CHAT missed many cases of autism; that is, it failed to identify children to be at risk who later received a diagnosis – therefore the sensitivity was unacceptably low.**

There are numerous possible reasons why the CHAT missed cases of autism at 18 months. First, each item on the CHAT was structured in such a way that the behavior in question had to be definitely present or absent. For example the key items were phrased "Does your child ever pretend?" This meant that to "fail" an item, the child must never have produced the behavior and this may have been too stringent. More likely is that reduced frequency of behaviors such as pointing or pretending may be important in detecting risk for autism. Second, the key items on the CHAT solely focused on joint attention and pretend play. The CHAT did not take into consideration other important behaviors that may be significant in the early identification of autism, including repetitive and stereotyped behaviors and sensory abnormalities. Third, screening at 18 months might have been too early to catch all children with autism since approximately 20-50% of children with autism exhibit developmental regression (Lord, Shulman & DiLavore, 2004) in language and/or social skills (Hansen et al., 2008) after 18 months. Lastly, during the 1990s when the CHAT was developed there was a noted increase in the prevalence of autism. The design of the CHAT was primarily based on aiming to detect what today would be called childhood autism, rather than the broader spectrum that includes AS, atypical autism, or PDD-NOS (it is relevant that AS was only officially recognized in 1994, during the decade of the CHAT studies).

In light of lessons learned through the course of these studies, **a revised version of the CHAT has been developed by Simon Baron-Cohen and his team.** The Quantitative Checklist for Autism in Toddlers (Q-CHAT) aims to enable parents to quantify autistic traits. The Q-CHAT bypasses the need for clinician observation, by relying entirely on parental report. If successful, this has the potential to reduce the burden on primary health care workers and could be a cost-effective method of screening large populations. The Q-CHAT retains the key items from the original CHAT but includes additional items that examine language development, repetitive and sensory behaviors, as well as other aspects of social communication. Each item contains a range of response options and does not force the parent to decide whether the behavior is definitely present or absent. This approach allows for the possibility that children at risk for autism and ASC show a reduced rate of key behaviors. In effect, this "dimensionalizes" each item (using a five-point scale of frequency), allowing for greater variability in responses and provides statisticians with more information with which to discriminate children who are developing typically from those on the developmental trajectory towards autism. Altogether, the Q-CHAT consists of 25 items, all of which endeavor to capture behaviors that may be characteristic of children who later receive a diagnosis of ASC. **All 25 items have been illustrated by a wonderful charity in the US, the Help Autism Now Society, founded by Linda and Paul Lee.** These illustrations help parents to understand about what each item is asking, and hopefully avoids misunderstandings. See Box 1 for some example Q-CHAT items and illustrations.

**Box 1: Example Q-CHAT items and illustrations**

SECTION 1

Please answer the following questions about your child by marking the appropriate circle.
Try to answer EVERY question if you can.

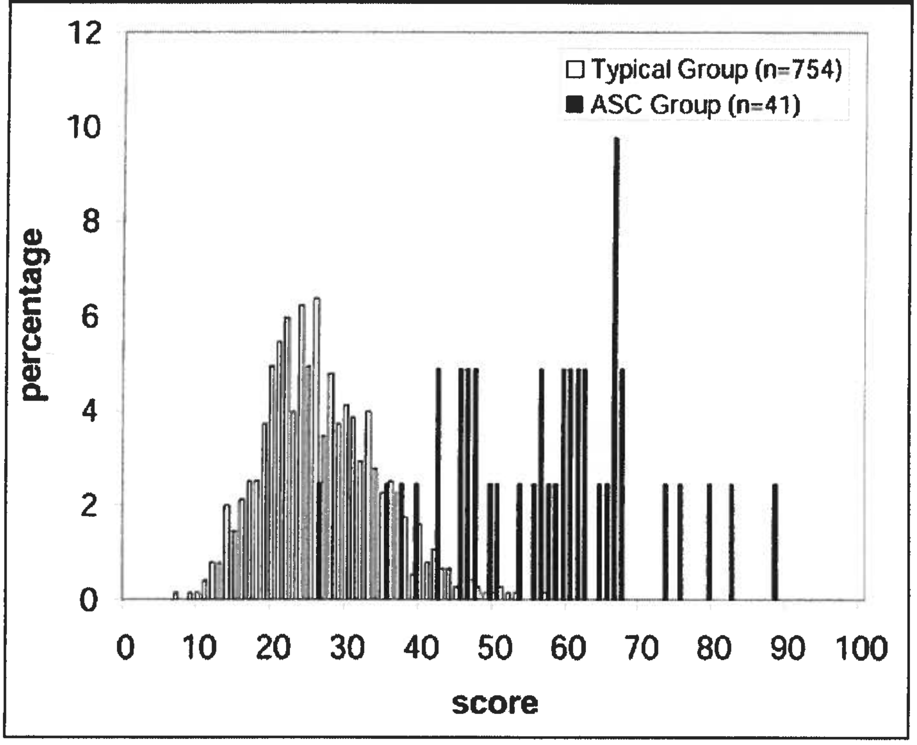
1. Does your child look at you when you call his/her name?
   - ○ always
   - ○ usually
   - ○ sometimes
   - ○ rarely
   - ○ never

2. How easy is it for you to get eye contact with your child?
   - ○ very easy
   - ○ quite easy
   - ○ quite difficult
   - ○ very difficult
   - ○ impossible

3. When you child is playing alone, does s/he line objects up?
   - ○ always
   - ○ usually
   - ○ sometimes
   - ○ rarely
   - ○ never

Our pilot study has provided encouraging results. Two groups of children were compared. First, a group of 160 parents of children who already had a diagnosis of autism were asked to complete the Q-CHAT. These children were older than the age at which the Q-CHAT is intended to be administered, but this group included 41 children who were all less than three years of age. A second group (754) of parents from a birth cohort of 18-24 month old toddlers also completed the Q-CHAT. The score distributions of children in the two groups were compared and a significant difference was found: **the group with autism scored higher on the Q-CHAT than the general population sample** (see Figure 1).

Figure 1: Comparison of Q-CHAT distribution between a selected subsample of Group 1 (N=41) and Group 2 (N=754) (from Allison et al., 2008)



Further, the distribution of scores on the Q-CHAT in the general population sample approximated a normal distribution.

This is the first toddler screening instrument specifically for detecting autism that has shown a range of scores in the general population that approximates a normal distribution. Interestingly, **boys scored significantly higher on the Q-CHAT than girls.** Sex differences have been found in other measures of social and communication abilities. For example, males score higher on the Childhood Autism Spectrum Test (CAST) (Williams, Allison et al., 2008); the Social Reciprocity Scale (SRS) (Constantino, Davis et al., 2003); and on the child, adolescent and adult versions of the Autism Spectrum Quotient (AQ), a quantitative measure of autistic traits in high functioning autism or AS in children, adolescents or adults of average IQ or above (Auyeung, Baron-Cohen, Wheelwright & Allison, 2008; Baron-Cohen, Hoekstra, Knickmeyer & Wheelwright, 2006; Baron-Cohen et al., 2001). The sex difference found here suggests two possibilities. First, boys may exhibit more difficulties in social, communication and rigid and repetitive behaviors than girls in early development (Leekam et al., 2007). Alternatively, the Q-CHAT may be more efficient at detecting autistic features in boys than in girls; therefore the sex difference found may simply be an artifact of the measurement instrument and sampling procedure. Per-haps the Q-CHAT is more sensitive to social and communication development difficulties in boys, and additional items would be required to identify more specific features in girls that are less obvious (Kopp & Gillberg, 1992; Wolff & McGuire, 1995) at this early age. Long-term follow-up of this pilot sample is ongoing to track the diagnostic outcomes of children who score high on the Q-CHAT. These data only represent initial psychometric work with this revised instrument.

**A large-scale project is currently underway that aims to fully validate the Q-CHAT.** We are undertaking to distribute 20,000 Q-CHATs to parents of toddlers aged 18-30 months in Cambridgeshire, UK. So far, we have sent out about 14,500 questionnaires and

> *"Long-term follow-up of this pilot sample is ongoing to track the diagnostic outcomes of children who score high on the Q-CHAT. These data only represent initial psychometric work with this revised instrument."*

have had about 3,500 responses. We have developed a sampling strategy that we hope will maximize the capture of potential autism cases. This involves sampling across the whole score distribution, rather than only calling in children for diagnostic assessments with a high score. All high scorers will be called in, as well as children with borderline and low scores (the chance of being selected decreases as the Q-CHAT score lowers). Most other screening studies, such as the Modified Checklist for Autism in Toddlers (M-CHAT) (Robins, Fein, Barton & Green, 2001), only call in for assessment those who "fail" the screen. While our sampling strategy is labor intensive, time consuming and expensive, we hope that the information that we gather about how the Q-CHAT performs across the whole score distribution will enable us to make valid recommendations about its utility. We are using the gold standard diagnostic measures, namely the Autism Diagnostic Observation Schedule (Lord et al., 2000), Autism Diagnostic Interview-Revised (Lord, Rutter & Le Couteur, 1994) as well as obtaining a measure of IQ through the Mullen Scales of Early Learning (Mullen, 1995), and a measure of adaptive ability through the Vineland Adaptive Behavior Scales (Sparrow, Cicchetti & Balla, 2005). We are blind to the child's Q-CHAT score at the time of the assessment to minimize expectation bias. Also, because we have children with low scores on the Q-CHAT, not every assessment is with a child who is likely to have developmental difficulties, and this also helps to reduce bias.

Few research groups have attempted population screening for autism in very young children. There are practicalities and inevitable problematic outcomes (e.g., low positive predictive value, high number of false positives, low response) associated with population screening, which make it a daunting task. Research with screening instruments like the Q-CHAT and the M-CHAT are longitudinal projects and require many years of follow-up. In the UK, barriers exist in attempting population health research such as accessing the population because of data protection legislation, poor response, attrition at various stages, and cooperation and collaboration with our National Health Service. As there is no standardized screening or compulsory developmental check-ups in the UK, there is no already available opportunity to have the health professionals themselves involved in the screening. Instead, the Q-CHATs have to be mailed to the family home. Despite concerted efforts to maximize response, 25-30% is a typical response to an unsolicited questionnaire of this nature. We feel that face-to-face contact with a trusted health professional would help to improve response, but there are so many resource implications that this cannot currently be considered. When response is low, it calls into question how representative the responders are of the general population. The amount of bias that could be attributed to the non-responders is unknown and is not measurable beyond comparison of general population statistics. **In our pilot study, we did find a larger proportion of parents with higher levels of education, from higher socio-economic strata than is found in the general population. In terms of population screening, this may have implications concerning access to services if the high socioeconomic groups are more inclined to complete screening questionnaires.** In fact, results from a recent prevalence study of autism showed those children who had been previously identified and diagnosed with autism were more common in families with well-educated parents (Baird et al., 2006). Despite these challenges, they are not valid reasons to give up on population screening for autism. In the UK at least, better methods must be found to work collaboratively with the health professionals who contend first hand with conditions like autism. It seems that in the US, a more collaborative approach to screening for autism occurs between clinicians and researchers, a model that the UK health system should follow. Ultimately, earlier detection of autism may lead to improved outcomes through the implementation of specific interventions, which will benefit not just the individuals themselves, but their families and society at large.

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## Cover Artist: Luis Huete

Step up to the plate

For this issue, we pursued contributions for the cover a little differently, providing our potential cover artists with a theme for their illustration. We asked them to draw how you would "step up to the plate." As many of you know, we need financial support to keep ANOC going. We have received extensive positive feedback regarding how much our readers enjoy the content, and we appreciate the affirmation. We are now asking that those of you who have enjoyed ANOC over the years "step up to the plate," and donate what you are able.

Thank you for your continued support!

Luis is a 7th grader who attends Washington Middle School in La Habra California. He attends the S.U.C.S.E.S.S. class taught by Miss Myers. As demonstrated by the drawing, Luis is a skilled artist, who likes objects to be orderly and systematic. The drawing on the cover is a result of a challenge given to the students in Miss Myers' classroom to illustrate how you "step up to the plate." Luis enjoys playing and watching baseball, and would love to attend an Angels baseball game someday.

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