

<b>Title</b>	Screening for autistic spectrum disorder at the 18-month developmental assessment: a population-based study
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## Introduction

Autism is difficult to detect in very young children on clinical assessment or using standard diagnostic instruments.<sup>1</sup> The average earliest age of diagnosis is approximately four or five years, although there is a trend towards earlier diagnosis in the pre-school age range.<sup>2,3</sup> Even with relatively earlier diagnosis, there is usually a gap (typically between 24 and 30 months duration) between the child's age when the parents first raise concerns, and the child's age at clinical assessment.<sup>4-7</sup> Delays in diagnosis disrupt the child and parents' lives, and delay the implementation of support services.<sup>8</sup> Evidence suggests early diagnosis and intervention greatly enhance long-term prognosis.<sup>9-12</sup>

Given the importance of early diagnosis, a screening instrument that can be easily administered to large samples of very young children would help identify those at-risk for autism. The Checklist for Autism in Toddlers (CHAT) addresses the need for earlier screening and identification of autism.<sup>13</sup> It is a screening instrument for autism designed to be administered to infants at 18 months of age. Primary health care providers can administer the CHAT. Therefore it can be used at the routine 18-month developmental check in Ireland. The CHAT instrument has been used to screen for autism at 18-month developmental assessment in the UK<sup>14,15</sup> and has been shown to identify potential cases of autistic spectrum disorder for full diagnostic assessment. The CHAT instrument has not been widely used in this age group in Ireland to date. We report findings from a population based screening study using the CHAT instrument in a sample of 2117 infants presenting to public health nurses for 18-month developmental assessment.

## Methods

### Sample Group

We used a cross-sectional study design. All Public Health Nurses (PHNs) who worked in counties Cork and Kerry during the target period were invited to act as data collectors. An open letter was sent to all PHNs inviting them to attend one of seven half-day training sessions offered at various locations in counties Cork and Kerry by members of the research team (AV and MF). PHNs at each training session were calibrated in the administration and scoring of the CHAT instrument, given a presentation on childhood autism, and the study protocol was thoroughly discussed. A total of 164 PHNs attended a training session and 95% agreed to assist with data collection (n=156).

**Figure 1:** Social class distribution of the study sample relative to the Southern Health Board Catchment area

The participating PHNs invited 2,684 parents and their infants to participate in the study. A total of 79% of those approached agreed to participate (n=2117). 51% of infants administered the CHAT were male (n=1088) and 49% were female (n=1029). The social class distribution of the sample group (n=1781 with available data) was broadly representative of the social class distribution of the former Southern Health Board area (Cork & Kerry) based on 2002 census data, allowing for sampling variation (Figure 1).

### CHAT Instrument and Field work

The CHAT instrument was employed in data collection. This is a 14 item interviewer-administered instrument divided into two sections: Section A includes 9 items administered to the parent and Section B includes 5 items based on interviewer observations of the infant.<sup>14</sup> The PHNs collected additional socio-demographic data including data on parents' occupation(s), parents' age, child's birth order and child's birth status (single or twin).

Participating PHNs administered the CHAT at the 18-month developmental check. The socio-demographic questionnaire was self-completed by the parent. Occupational data was coded into social class categories using the methodology employed in the 2002 Irish Central Statistics Office social class categorisation.<sup>16</sup> The infants' social class category was coded on the basis of the higher of the parents social class categories.

Each completed CHAT was scored by the PHN into one of three categories: high, medium or low risk for autism, based on a standard scoring system. If an infant scored medium or high risk for autism at the first administration, a second screening was administered approximately one month later. All second screenings were administered by the same PHN that conducted the first screening. Infants who scored medium or high risk for autism at two administrations of the CHAT were categorised as having screened positive for autism and were offered full diagnostic assessments by an experienced clinical psychologist (MF), approximately six months after the second screening.

Data were analysed using SPSS version 9.0. The main outcome measures were a medium or high-risk score following two administrations of the CHAT screening instrument and a positive diagnosis of autism after clinical assessment.

## Results

A summary of screening outcomes at the first screening, second screening and the outcome of clinical assessment is provided in Figure 2. A total of 29 infants from the study sample of 2117 were characterised as 'Medium' or 'High' risk at first screening: an estimated prevalence rate of 137.0 per 10,000 (95% CI: 91.9 to 196.1). A total of 7 of the 29 first screen positive infants were positive (medium or high risk) at second screening, 12 were low risk and 10 parents refused to participate. On subsequent clinical assessment of the 7 infants screening positive on first and second assessment, three were diagnosed with autism, one with learning disability and the remaining three were found to be at low risk for autism. On clinical assessment of five of the ten infants whose parents declined second screening, four were diagnosed with autism and one with learning disability. Thus, following this screening exercise, a total of 7 children received a diagnosis of autism: an overall prevalence of clinically diagnosed autism of 33.1 per 10,000 (95% CI: 13.3 to 68.0). No information was obtained on five of the 10 infants who were eligible, but did not participate in a second screening.

## Discussion

This study represents the first assessment of the feasibility of routine administration of the CHAT instrument as a screening tool for autism in an Irish sample of children aged between 18 and 20 months, attending for routine developmental assessment. The findings suggest that use of the CHAT questionnaire is feasible in this setting and that a significant number of autism cases can be detected.

In the UK, Baron-Cohen et al.<sup>14</sup> screened 16,235 infants at 18 months using the CHAT instrument. They reported a positive screening rate for autism (medium or high risk CHAT score) of 251 per 10,000 (95% CI: 226-274) following the first administration of the instrument, a somewhat higher rate than that observed in this sample: 137.0 per 10,000 (95% CI: 91.9 to 196.1). As in the current study, a significant proportion of children who screened positive on first assessment did not return for a further assessment. In the UK study, children who scored medium or high risk after two screenings (n=32) were given full clinical assessments at 42 months and 10 cases of autism were diagnosed. Thus the UK screening exercise yielded 12 cases of autism per 10,000 children screened on at least one occasion (95% CI: 2.9 to 11.3) as compared with 33.1 per 10,000 (95% CI: 13.3 to 68.0) in the current study. Thus the yield in terms of previously undiagnosed cases in the current study appears high relative to the earlier UK study. However comparisons between the two studies are constrained by the differences in sampling strategies and drop out rates.

The involvement of public health nurses in routine clinical practice, but with formal training in the use of the CHAT instrument, represents a significant strength of the study. However the relatively small sample size is a significant limitation. Although a good response rate for first-time screening was achieved (79%), the sample was small for the relatively rare condition of autism limiting the precision of the prevalence estimate. Thus a precise and accurate estimate of the true rate of autism in the catchment area could not be derived from the study.

Furthermore the diagnostic test performance of the CHAT instrument limits the accuracy of the prevalence estimate of autism. It is reported to have a sensitivity of 38% and specificity of 98% for identifying autism in this age group.<sup>15</sup> Assuming a similar test performance of the CHAT in our study it is likely that the prevalence of autism in our sample has been underestimated. We were not able to determine the overall diagnostic performance for the CHAT because the gold standard for diagnosis of autism was not applied to the entire sample. The CHAT instrument has been modified and initial results from the Modified Checklist for Autism in Toddlers (M-CHAT) suggest this instrument may have higher test performance but it has not been comprehensively evaluated in a general population sample.<sup>17,18</sup> If confirmed, this represents significant progress in the early detection of autism and pervasive developmental disorders and we should prioritize work on the evaluation of this instrument in routine developmental assessments in Ireland.

The use of the CHAT within the broader context of developmental infant screening deserves further consideration. For example Honda and Shimizo<sup>19</sup> reported very good detection rates for autism in serial screenings of infants at 18-months and 36 months of age in Japan. In this study, a general screening instrument was used first to identify children who were likely to have developmental problems not specific to autism. Children testing positive were consequently followed-up with more specific instruments.

In summary, we have shown that the CHAT instrument, administered by public health nurses at the 18-month developmental assessment, represents a potentially feasible strategy for the early diagnosis of autism. It is an inexpensive, quick

and simple instrument for PHNs to use. Given the evidence that early diagnosis improves prognosis in autism<sup>20</sup> there is a clear need for further work addressing the use of the CHAT instrument in routine developmental assessment in Ireland.

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Comments:

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