CURRENT TOPIC

Screening and surveillance for autism and pervasive developmental disorders

G Baird, T Charman, A Cox, S Baron-Cohen, J Swettenham, S Wheelwright, A Drew

Screening and surveillance

Screening and surveillance are different but related activities involving the detection of impairments with a view to prevention or amelioration of consequent disability and handicap. Screening is the prospective identification of unrecognised disorder by the application of specific tests or examinations. Surveillance refers to the ongoing and systematic collection of data relevant to the identification of a disorder over time by an integrated health system.

The review by Hall[1] in *Health for all children* concluded that most screening tests that set out to identify neurodevelopmental disorders do not meet the stringent criteria outlined by Cochrane and Holland[2] and Wilson and Jungner.[3] In some conditions, for example language disorders, this is because there is uncertainty about "caseness" and tests tend to have low sensitivity and specificity.[4 5] This is particularly the case for screening tests that attempt to identify a specific condition rather than general developmental delay, and for the identification of relatively rare disorders. In the latter case, even when the sensitivity and specificity of a screen remain constant, the positive predictive value (the proportion of children with a positive screen result and who have the disorder) is lower the rarer a disorder is within the population.[6]

The concept of developmental surveillance is a parent–professional partnership that takes a broader look at developmental and behavioural skills and progress over time. It combines the observations of parents with the developmental knowledge of the professional and the deployment of specific tests. There is evidence that the use of screening instruments in combination with asking parents about their concerns improves the efficiency of an instrument.[7 8]

However, the number and type of concerns that parents have about their child's behaviour and development determine whether using a screening instrument within the clinic setting is effective. For example, Glascoe, in a series of studies using the Parents' Evaluations of Developmental Status (PEDS),[9] has shown that when parents had a single significant concern about their child's development (or there was a communication barrier because parents did not share the same first language as the paediatrician) the use of a screening test

increased the specificity of onward referral at only a slight cost to sensitivity.[10] However, when parents had two or more concerns about their child's development (for example, self help, social, or receptive language difficulties), use of additional screens led to an unacceptable drop in sensitivity, indicating that onward referral for diagnostic evaluations is the best course of action in such cases.[10]

Despite the challenges of screening for neurodevelopmental disorders, there is professional and public agreement that early identification of child health problems is desirable. Notably this includes identification of developmental disabilities as well as medical diseases.[11 12] Further, over the last decade the emphasis has shifted from screening in the preschool years, to infants from birth to 2 years of age.[11]

Autism and the pervasive developmental disorders

Pervasive developmental disorders (PDDs), of which childhood autism is the prototypic disorder,[13 14] are specific developmental disorders in which there are qualitative impairments in social interaction and communication combined with a restricted repertoire of interests, activities, and behaviours, with onset in early childhood. In any paediatric clinical service that assesses developmental problems in preschool children they are an important part of the differential diagnosis from the more common problems of speech and language delay, general developmental delay, and behavioural difficulties. In part this is because most (but not all) children with autism and PDD have other learning problems, significant language delay or disorder, and behaviour problems. In the high functioning group where language milestones are not delayed and cognitive skills are in the average or superior range, the diagnosis is often not made until school age, or even later.[15] A multidisciplinary approach to assessment is required because of the multiplicity of developmental and behavioural problems with which these children present. The composition of teams varies across centres, but commonly includes a paediatrician, a speech and language therapist, a clinical psychologist, and a physiotherapist; diagnosis should be made on data from all sources of information

Newcomen Centre and Bloomfield Clinic, Guy's, King's College and St Thomas' Hospital Medical School, London, UK
G Baird
A Cox
A Drew

Institute of Child Health, University College London, UK
T Charman

Department of Human Communication and Science, University College London
J Swettenham

Departments of Experimental Psychology and Psychiatry, University of Cambridge, UK
S Baron-Cohen
S Wheelwright

Correspondence to:
Dr G Baird, Department of Paediatric Neurology, Newcomen Centre, Guy's and St Thomas' Medical School, St Thomas St, London SE1 9RT, UK
Gillian.Baird@
gstt.sthames.nhs.uk

including behaviour in two settings. Other disciplines, such as child psychiatry, can also contribute to the assessment process if this is indicated in the child and family's presentation.

The aetiology of autism is thought to be predominantly genetic,[16 17] but other medical causes need to be excluded, especially if there are additional neurological or dysmorphic findings or where there is a history of regression or loss of skills.[18 19] From the clinical perspective, there is often difficulty in the differential diagnosis of autism and related PDDs from a number of other developmental problems, in particular severe and profound general developmental delay, language disorder, and hyperkinetic and attentional disorders. Co-morbidity can further complicate the diagnostic picture, as autism and PDD can coexist with hyperkinetic and attentional disorders, obsessive compulsive disorder, and developmental disorders of motor function, as well as specific and general learning problems.[20] Differential diagnosis can be particularly difficult in young children with severe and profound developmental disability and in children with superior intelligence.

Why screen young children for autism?
In some conditions screening and immediate medical treatment can prevent disability (for example, phenylketonuria) or substantially ameliorate the consequent disability, as in sensori-neural deafness. In conditions like muscular dystrophy, early diagnosis leads to genetic advice and prenatal diagnostic tests can be offered. What evidence is there for a similar position in autism? The risk of a second child having autism when the first has the diagnosis is 5% (one hundred times the reported prevalence),[21] and the chances of a more general problem in social communication or cognitive development are several times higher still.[22] There is no prenatal diagnostic test, but parents need to have this information as soon as possible if they are to make personal choices about extending their family based on existing knowledge rather than ignorance.[23]

There is also the possibility that early diagnosis followed by appropriately targeted intervention may improve outcome, especially in management of behaviour, functional skills, and communication problems. There is some, although not uncontroversial, evidence of the benefits of behavioural early intervention programmes.[24–26] However, behavioural programmes have begun to incorporate elements from communication based and developmental approaches, and a range of treatment approaches across a continuum from discrete trial traditional behavioural approaches to social pragmatic developmental approaches can now be identified.[27] Preliminary findings from ongoing studies show positive outcomes in terms of IQ gains and reductions in symptom severity for both behavioural[28] and education based approaches.[29] There is increasing agreement that age of the child and an emphasis on developing communication form important elements of intervention programmes for which some positive outcome data exist.[30 31]

Until recently there has often been a considerable delay between parents' recognition that there may be something amiss with their child's development and the diagnosis of autism. When parents become concerned about their child's development they need rapid access to diagnostic and support services. Too often this does not happen.[32] Howlin and Moore[33] have recently reported a study of 1295 families in the UK. Fifty per cent of parents reported recognising problems by 2 years and 93% by 3 years. Half had received a diagnosis by age 5 but for the rest long delays and multiple referrals were a common experience, and there was considerable regional variability. The encouraging finding was that a trend to a younger age of diagnosis in more recently diagnosed cases existed (for example, for children currently under 5 years old the mean age of diagnosis was 2.7 years, compared with 6.8 years for those now 10–15 years old). The satisfaction rating with the process of referral and diagnosis was also much higher when diagnosis was at a younger age.

Providing a prompt service to address parental concern is of course very different from finding a problem that a parent does not suspect. Autism is a disorder that will inevitably be noticed by parents at some stage, and earlier rather than later given the present high profile of autism in the media. Parent groups with whom we have raised the topic of screening have been divided about whether they would rather have known of a potentially severe developmental problem before they themselves noticed or not. Some strongly stated that they would rather enjoy ignorance for longer; others wanted to know as soon as possible. These different views need to be borne in mind by health professionals. The difficulties of recognition, belief, and acceptance are far from easy when the professional is giving completely unexpected information. The negotiation of realisation of a possible problem is one of the skills of effective surveillance. For a parent to make use of information about their child it first has to make sense and they have to be ready to agree on it. Further, many of the intervention programmes in autism that are said to be successful demand both commitment and knowledge on the part of the parent.

Early indicators of autistic development
It has long been acknowledged clinically that some parents report becoming aware of abnormal development in the first year of life. Wing[34] noted that extremes of temperament, abnormal social relating, abnormal eye contact, and unusual visual interests are among the comments made by parents. Empirically, two sources of information are available regarding the earliest indicators of autistic development: retrospective parental report of early symptoms and videotape taken before the child was diagnosed (for reviews see Charman[35] and Stone[36]). Gillberg and colleagues[37] reported a prospective study and compared the discriminating items with those that discriminated according to retrospective parental report in a separate (older) sample. Isolation from surroundings,

failure to play like other children, and apparent deafness were the prospective study items that discriminated autism from developmental delay and normality. Empty gaze, failure to attract attention, lack of smiling, and poor imitation of movements were strong predictors both retrospectively and prospectively. Ohta and colleagues[38] found that the early parental concerns that discriminated autism from general developmental delay included a poor response to others, poor peer relationships, and ignoring others as if deaf. Parents of children with autism also frequently reported two other symptoms: concerns over delayed speech, and restlessness and hyperactivity. However, they were also commonly reported by the parents of children with developmental delay without autism, and thus would not act as specific indicators for autism.[35]

Another source of information regarding the early development of children with autism is home videos taken before the child was diagnosed. Adrien and colleagues[39] found that within the first year children with autism showed impairments in social interaction, lack of social smile, lack of appropriate facial expression, hypotonia, and poor attention. In the second year of life additional impairments characterised the children with autism, including ignoring people, preference for aloneness, lack of eye contact, lack of appropriate gestures and lack of emotional expression. In a study examining home videos taken at first birthday parties, Osterling and Dawson[40] found that children with autism were less likely to look at others, to show an object or point to objects, and to orient to their name, compared to typically developing controls. Recently, Baranek[41] has shown that abnormalities in orientation to visual stimuli, aversion to touch, and delayed response to name all characterise autism (but not developmental delay or typical development) as early as at 9 months of life. Two studies have attempted to use contemporaneous health record information retrospectively[42] and prospectively (Lister-Brook, personal communication). Lister-Brook found that health record information in the first year of life did not identify characteristic autistic behaviours at less that 12 months of age. Johnson and colleagues[42] found that information on motor, visual, hearing, and social development did not discriminate children with autism from developmentally delayed controls at either 6 or 12 months. However, by 18 months the children with autism were reported to have more problems in the social and hearing and language domains.

These findings and the research of Sigman[43] and Mundy[44] have shifted the focus for early detection of autism from language to early social and orientating behaviours. There is some evidence of early abnormalities in sensory, motor, and repetitive and stereotyped behaviours; when such behaviours are present they are highly characteristic of autism. However, most studies concur that the best discriminators at this age are likely to be the social and communicative impairments. In particular, joint attention behaviours emerge as the core deficits in early autistic development.[45 46]

Developmental screen and rating scales for autism

Many general developmental screening instruments exist. However, even those for which evidence of robust psychometric properties exist, for example, the Denver Developmental Screening Test–Revised,[47] the BRIGANCE Screens,[48] the Child Development Inventories,[49] and Parents' Evaluations of Developmental Status,[9] are likely to only identify children with significant developmental delays. Further, the target of these screens is to identify the considerable proportion of the general population who have developmental delays in the motor, language, and cognitive domains, and they do not specifically identify when a child may have autism or a related PDD.

While a number of rating scales that measure severity of autistic symptoms exist, these are primarily used to assess clinically referred samples (for example, Autism Behavior Checklist[50]; Childhood Autism Rating Scale[51]; and Infant Behavioral Summarized Evaluation[52]). Other schedules such as the Autism Diagnostic Interview–Revised,[53] the Autism Diagnostic Observation Schedule–Generic,[54] and the Diagnostic Interview for Social and Communication Disorders[55] are detailed interview and observation schedules that are useful clinically and in research, but they are time consuming and require rigorous training in their administration.

However, recently a number of checklists and questionnaires have been developed that could act as screening tools at either the level I (primary) or level II (secondary) health system tier. For example, the Pervasive Developmental Disorders Screening Test has different schedules for level I and level II use.[56] The Autism Screening Questionnaire has been shown to discriminate between already assessed samples of children and adults with autism and PDD, and comparison samples.[57] The Pervasive Developmental Disorders Questionnaire (see Baird and colleagues[58] for a summary) has been shown to measure autistic symptoms, although it has not yet been evaluated as a screening tool in either a clinic or a general population.

A number of scales have also recently been developed to measure symptom severity in individuals with autism with average intelligence ("high functioning autism") and individuals with Asperger syndrome. Ehlers and Gillberg[59 60] developed a population screen to identify Asperger syndrome in school age children; this has been successful in identifying cases from relatively small population samples. Other similar scales have been developed (Australian Scale for Asperger syndrome,[61] Autism Spectrum Quotient[62]), although their properties have not yet been systematically evaluated.

A prospective screening study for autism

Until recently no population screen to identify autism and PDD in preschool children existed. Drawing on the evidence of early features of

autism, in particular that the abnormalities that most clearly differentiate children with autism are social orienting behaviours including joint attention and pretend play, a new instrument was developed. The CHAT (Checklist for Autism in Toddlers) was designed to prospectively identify autism at 18 months of age. This age was chosen as an appropriate screen "window" because joint attention and pretend play typically emerge at this time in normal development.[63] The CHAT assesses simple pretend play (appropriate use of a teaset, doll play, object substitution) and the joint attentional behaviours, pointing for interest (in combination with eye contact) and following gaze, by parental report and health practitioner observation through direct testing. In a first study,[64] the CHAT correctly predicted the four undetected cases of autism at 18 months of age from among 41 siblings of children already diagnosed with autism and therefore at higher risk of developing autism. To test the effectiveness of the CHAT in a large general population, health visitors, general practitioners, and community medical officers in the South Thames region of the UK used the questionnaire with 18 month old infants as part of routine health screening.[58 65] Of the total population of 40 818 infants eligible for screening, 16 235 (39.8%) were screened using the CHAT (mean age 18.7 (SD 1.1) months). This proportion reflected the fact that only children ±2 months either side of 18 months of age were included in the study. Key items are those that measure joint attention (following a point, pointing for interest) and pretend play as reported by parents and observed by professionals either at home or the clinic (see table 1). Some children with profound developmental delay, including all those with severe sensory and motor impairments had been excluded. Apart from children with profound sensory and motor impairment, exclusions were not part of the original design of the study but reflected the health practitioner decision not to impose additional assessment on parents of children with preidentified, severe developmental problems. In order to minimise false positives, a two stage screening procedure was adopted. Children who were initially screen positive received a second administration of the screen one month later.

Used in this two stage way, the positive predictive value of the screening instrument was high (83% for autism and PDD using the highest risk threshold). However, there was poor

sensitivity (18%), indicating that four fifths of the children subsequently identified as showing autistic development in the study population were missed on screening. If a one stage screening procedure only had been adopted, the proportion of children with autism identified increased to 38%, although in clinical use this would have entailed the assessment of more screen false positives. However, the positive predictive value for identification of all (PDD and non-PDD) developmental problems was 48% (see Baird and colleagues[58] for full details). What is clear is that while 9% of the screened population were reported to not produce simple pretend play at age 18 months and 4.5% were reported to not point for interest, failing a combination of joint attention and pretend play items (by both parental report and health practitioner observation, and on both administrations of the screen) indicated a significant risk for developing autism.

A modification of the CHAT (M-CHAT[66]) has been developed in the USA. While preliminary data suggest it is able to discriminate well between autism/PDD and developmental and language delays among children referred to an early intervention service, its properties as a general population screen have not yet been evaluated.

Additional benefits of the screening study
In a current study using the CHAT in the South Thames region to identify children with autism at age 20 months for inclusion in an intervention study, only the key screening items measuring joint attention and play behaviours (see table 1) were included in a shortened version of the screen, again administered at 18 months. In order to minimise screen false positives, they were asked to refer children who not only failed all the key items but in whom they were also concerned about possible autism—that is, they were asked to exercise clinical judgement. The children notified as failing all pointing and pretence items by parent report, confirmed by professional observation had a repeat CHAT by telephone within two weeks. Of 51 children referred to the study, five passed on retest by telephone. Of the remaining 46, 31 had autism, five PDD, six a receptive–expressive language disorder, two global developmental delay, and one attention deficit–hyperactivity disorder. Only one child appeared clinically normal on detailed assessment. This confirms the high positive predictive value of the CHAT, and suggests that it may be increased in the one stage administration when combined with a professional clinical judgement of concern regarding the child's development. Sensitivity cannot be estimated from this study. However, it is likely that the CHAT could prove to be a useful clinical tool at the primary health care level (for use when practitioners and/or parents have some concerns about the child's development), even if it is not used as a general population screen. Remember, though, Glascoe's caution about the use of screening instruments when parents have multiple concerns about their child's development.[10]

Table 1 The five key items on the CHAT screen

Ask parent
Does your child ever PRETEND, for example, to make a cup of tea using a toy cup and teapot, or pretend other things?
Does your child ever use his/her index finger to point, to indicate INTEREST in something?

Health practitioner observation
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?
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?
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? To record YES on this item the child must have looked up at your face around the time of pointing.

One additional benefit of a screening programme may be that the diagnosis of autism within the whole population (including screen false negatives) is made earlier. Of the children with a diagnosis of autism from the whole, eligible population (40 818 children) from which the 16 235 were screened using the CHAT, the age of the first concern for the whole group was 21 months (range 3–42 months), for first referral 33 months (range 19–61 months), and for diagnosis 42 months (range 21–74 months). A total of 91% were diagnosed by 5 years of age, indicating that the use of the screening instrument and teaching of the health visitors may have resulted in increased confidence in surveillance. Anecdotal discussion with health visitors appeared to confirm this as many commented on the usefulness of knowing what prelanguage and presocial skills could reliably be looked at during the 18 month check. Such comments also apply at 2 years, now the preferred age of screening in the UK. However, we do not know what the positive predictive value and sensitivity of the screen would be if used routinely at this age.

Reliability of early diagnosis

Screening should lead on to skilled diagnosis and also an efficient and prompt treatment service; one without the other is a source of frustration to parents and professionals alike. How reliable is the early diagnosis of autism and is diagnosis stable from the second year of life through to school age? Gillberg and colleagues[37] reported on 28 children referred with possible autism aged less than 3 years. At follow up all continued to have some developmental problem. Gillberg *et al* made a diagnosis of autism in 75% of cases and this judgement was confirmed at follow up. Some of the children were very young, one only 5 months (but with infantile spasms which are known to be associated with later autism). Lord[67] reported 30 children aged 2 years, referred with possible autism. A variety of assessments were used—the ADI-R,[53] the nonverbal modules of the ADOS-G,[54] and the CARS[51]—as well as clinical judgement in deciding whether the child would be predicted to meet ICD-10 diagnostic criteria at 3 years. Assessments were repeated at 3 years of age. This study confirmed that clinical judgement was valid at 2 years and stable. Only one child was diagnosed as having autism at age 2, who at 3 years was thought to have a receptive and expressive language disorder. The standardised measures had good validity at age 3, but less so at age 2. Stone and colleagues[68] also showed good stability of diagnosis from 2 to 3 years. In another study using information from several diagnostic centres, Lord and colleagues[69 70] found that the ADI-R[53] effectively differentiated autism from mental handicap and language impairments, including in the preschool years. Reliable diagnosis is possible even for high and low functioning individuals if information from history is included as well as current functioning. Validity of standardised assessment instruments (ADI-R, ADOS) is less good with children with a mental age below 18 months.

In the CHAT study, diagnosis of autism or PDD at age 20 months proved reliable at follow up at age 42 months in all but one case (see Cox and colleagues[71] for details). However, the differentiation of PDD from other developmental delays at 20 months was less accurate. Several children later diagnosed as having PDD received a presumptive diagnosis of general developmental delay or language delay at 20 months. The consensus from these studies is that diagnosis of childhood autism (ICD-10) is reliable at age 3 but can be diagnosed earlier, and that experienced clinical judgement, taking information from a variety of sources, is most reliable. Diagnosis of the broader range of PDDs is less reliable.[68 71]

Clinical work is often concerned with those children who do not clearly meet full criteria for childhood autism but who have apparently milder social problems or where there are mixed developmental difficulties. Clinical experience also suggests that some children who show definite features of autism earlier make remarkable developmental progress. Therefore caution must be used, especially under 3 years, for those children with features of the broader autistic spectrum who may attract a PDD diagnosis. It is these authors' experience that parents understand the difficulties of certainty in developmental assessment. Most appreciate honesty on professionals' part about precise prognosis on a very young child and can understand a frank discussion about the possible outcomes if accompanied by appropriate advice and help for intervention. Understanding why one's child behaves as he/she does is half way to doing something about it.

Regression in autism

Some studies of autism have commented on the fact that in 15–30% of children there is a period of stasis of development and even frank loss of skills, most commonly speech (usually before the 10 word stage had been reached).[72] This is often accompanied by social withdrawal to "a world of his own" with less gaze monitoring and a lack of response to speech. Repetitive play behaviours are sometimes noted at this time. There is no loss of physical skills. Sleep and eating habits may be disturbed. No explanation exists for the fact that this pattern is shown in some children and not others, and the reliance on retrospective parental report of behaviour limits our knowledge of how widespread such a developmental course is. However, the younger the child is at the time of history taking, the more common is the reported history of regression, which occurs in up to 40% of cases.[73] The common time for change to be noted is 15–19 months, but if regression is later in its onset following a clear period of normal development to 3 years of age or beyond, developmental disintegrative disorder is the term used. The important clinical point is that medical causation should be excluded, most notably subclinical epilepsy similar to the Llandau–Kleffner syndrome.[73]

Very early screening methods may miss late onset autism (one of the first birthday videos of Osterling and Dawson contained such a child). We anticipated that using the CHAT screen at age 18 months, after most regressions in late onset autism are reported to occur, would reduce the false negative rate. However, as we report above, three fifths of children with autism were not identified by the screen. A review of the false negatives from the study shows that often parents reported at the time that their children showed pointing and/or pretend at 18 months while the professional had failed the child on the item. When a subsequent detailed history was taken from the parents after they had received a diagnosis of autism, they thought that at 18 months their child had probably not pointed (or pointing only occurred in the context of requesting and not sharing interest), neither had they pretended. One consideration is that an overriding wish or belief that the child was normal may have led to the conviction of a skill being present when in fact it was not. The lesson to draw from this is that such biases will compromise the sensitivity of the screen and that existing health surveillance procedures must be maintained for screen negative children.

Should we systematically screen for autism?

The CHAT study has shown that persistent absence of joint attention and pretence behaviours from 18 months are high risk predictors for autism. Should a screening programme for autism be launched, even assuming that all the appropriate services for diagnosis and treatment are in place (a big IF)? A recent consensus panel with representatives of nine professional organisations and four parent organisations, convened by the National Institutes of Health in the USA, positively recommended the use of developmental screening, including specific screening for autism and related PDDs, at each well child visit during infancy and the preschool years.[74–76] In contrast, a recent review on the utility of screening for speech and language delays concluded that limitations in the sensitivity and specificity of available screening instruments, as well as difficulties in identifying the boundaries of "caseness" in relation to established treatment efficacy and need, meant that universal population screening could not be recommended.[4 5] These problems are not unique to identifying speech and language delay, nor autism and related PDDs, but are common to the identification of developmental delays, not only in the field of neurodevelopmental disorders but also more broadly in health surveillance.[1 77]

In relation to autism and PDDs, the CHAT is the first attempt to develop a general population screen that we are aware of, and the instrument parameters are reported in detail in our six year follow up report.[58] The definition of "caseness" is clearly a problem within the field, although this is less so of children with autism than the less prototypic manifestations found in children with related PDDs. In terms of established treatment efficacy, while there are many advocates for the benefits of early intervention, our current knowledge of which programmes benefit which children in which ways remains nascent.[25 30 31] Naturally, parents wish to do the best for their children as early as possible and once a problem is identified and characterised as an autism spectrum condition, parents may advocate for treatment and education services, whatever their empirical status. There may be other important benefits of an early diagnosis that are not encompassed by measurement of features specific to autism. Firstly, it helps to know what one is dealing with. Misunderstood behaviour can set up patterns of parental response that may make later treatment more difficult for all concerned. There is also the impact on the health and behaviour of other family members. In addition, parents' and services' views about the importance of early information on genetic risks may be changing, and a desire for more systematic genetic counselling might provide an impetus to early identification.[23] Further, the usefulness of highlighting the importance of preverbal communicative and social behaviours, especially those of joint attention, has provided very helpful information in the broader surveillance of children with social communication delays and disorders and in the teaching of primary care practitioners responsible for surveillance.

Children who are delayed in the acquisition of these skills are at risk of persistent problems in social or communicative development, even if they will not go on to meet diagnostic criteria for autism or a related PDD. This broader group of children may benefit from intervention and also from behavioural advice, and some evidence exists for their role in the prevention of secondary problems. The CHAT programme was a research project and parents were asked to take part at a time when the sensitivity and specificity of the CHAT were unknown. Thus, the focus of the study was explained to them as a research project into the development of communication. In clinical practice there is a need for screening to be absolutely explicit with parents. Not knowing what disorders are being looked for is unacceptable. Explanation of exactly what screening can be carried out and negotiation of parents' agreement involves the kind of discussion that makes developmental problems more easily comprehensible, including the stages to diagnostic assessment and hence treatment.

Conclusions

According to the American Academy of Pediatrics in the USA, systematic search should be made to identify developmental disorders by the healthcare services[11]; following identification of a disorder, a referral for intervention is now mandatory in the USA (Individuals with Disabilities Education Act, 1997). The high specificity and positive predictive value of the CHAT means that it could be used as a screening instrument within a broader surveillance programme to identify cases before they had come to attention by other means. Its limitation is its low sensitivity,

with the majority of cases being missed. Hence, the need for it to be placed within a broader surveillance programme. However, it is our view that one effect of the project was an increased knowledge about and understanding of autism among health practitioners in the districts where the screen was used. It appears that this, in turn, resulted in earlier referral and diagnosis of children who had autism but who were not identified by the screen, thus contributing "additionality" to the existing surveillance mechanisms.

1 Hall DMB. *Health for all children. The report of the Joint Working Party on Child Health Surveillance*, 3rd edn. Oxford: Oxford University Press, 1996.

2 Cochrane A, Holland W. Validation of screening procedures. *Br Med Bull* 1969;**27**:3–8.

3 Wilson J, Jungner G. Principles and practice of screening for disease. *Public Health Papers*. No. 34. Geneva: WHO, 1968.

4 Law J, Boyle J, Harris F, *et al*. The feasibility of universal screening for primary language delay: findings from a systematic review. *Dev Med Child Neurol* 2000;**42**:190–200.

5 Law J, Boyle J, Harris F, *et al*. Screening for primary language delay: a systematic review of the literature. *Health Technol Assess* 1998;**2**:1–184.

6 Clark A, Harrington R. On diagnosing rare disorders rarely: appropriate use of screening instruments. *J Child Psychol Psychiatry* 1999;**40**:287–90.

7 Glascoe FP. Parents' concerns about children's development: prescreening technique or screening test? *Pediatrics* 1997;**99**:522–8.

8 Glascoe FP. The value of parents' concerns to detect and address developmental and behavioural problems. *J Paediatr Child Health* 1999;**35**:1–8.

9 Glascoe FP. *Parents' evaluations of developmental status*. Nashville, TN: Ellsworth & Vandermeer Press, 1997.

10 Glascoe FP. A method for determining how to respond to parents' concerns about development and behavior. *Ambulatory Child Health* 1999;**5**:197–208.

11 American Academy of Pediatrics, Committee on Children with Disabilities. Screening infants and young children for developmental disabilities. *Pediatrics* 1994;**93**:863–5.

12 Robinson R. Effective screening in child health. *BMJ* 1998;**316**:1–2.

13 American Psychiatric Association. *Diagnostic and statistical manual of mental disorders*, 4th edn (DSM-IV). Washington, DC: American Psychiatric Association, 1994.

14 World Health Organisation. *Mental disorders: a glossary and guide to their classification in accordance with the 10th revision of the International Classification of Diseases: research diagnostic criteria (ICD-10)*. Geneva: WHO, 1993.

15 Gillberg C, Nordin V, Ehlers S. Early detection of autism. Diagnostic instruments for clinicians. *Eur Child Adolesc Psychiatry* 1996;**5**:67–74.

16 Rutter M, Bailey A, Simonoff E, Pickles A. Genetic influences and autism. In: Cohen DJ, Volkmar FR, eds. *Handbook of autism and pervasive developmental disorders*, 2nd edn. New York: Wiley, 1997:370–87.

17 Szatmari P, Jones MB, Zwaigenbaum L, MacLean JE. Genetics of autism: overview and new directions. *J Autism Dev Disord* 1998;**28**:351–68.

18 Dykens EM, Volkmar FR. Medical conditions associated with autism. In: Cohen DJ, Volkmar FR, eds. *Handbook of autism and pervasive developmental disorders*, 2nd edn. New York: Wiley, 1997:388–407.

19 Gillberg C, Coleman M. Autism and medical disorders: a review of the literature. *Dev Med Child Neurol* 1997;**38**:191–202.

20 Gillberg C. Neuropsychiatric disorders. *Curr Opin Neurol* 1998;**11**:109–14.

21 Bolton P, Macdonald H, Pickles A, *et al*. A case-control family history study of autism. *J Child Psychol Psychiatry* 1994;**35**:877–900.

22 Le Couteur A, Bailey A, Goode S, *et al*. A broader phenotype of autism: the clinical spectrum in twins. *J Child Psychol Psychiatry* 1996;**37**:785–801.

23 Simonoff E. Genetic counselling in autism and pervasive developmental disorders. *J Autism Dev Disord* 1998;**28**:447–56.

24 Gresham FM, MacMillan DL. Early intervention project: can its claims be substantiated and its effects replicated? *J Autism Dev Disord* 1998;**28**:5–13.

25 Howlin P. Practitioner review: psychological and educational treatments for autism. *J Child Psychol Psychiatry* 1998;**39**:307–22.

26 McEachin JJ, Smith T, Lovaas OI. Long-term outcome for children with autism who received early intensive behavioural treatment. *Am J Ment Retard* 1993;**97**:359–72.

27 Prizant BM, Wetherby AM. Understanding the continuum of discrete trial traditional behavioural to social-pragmatic developmental approaches in communication enhancement for young children with autism/PDD. *Semin Speech Lang* 1998;**19**:329–52.

28 Sheinkopf SJ, Siegel B. Home-based treatment of young children with autism. *J Autism Dev Disord* 1998;**28**:15–23.

29 Ozonoff S, Cathcart K. Effectiveness of a home program intervention for young children with autism. *J Autism Dev Disord* 1998;**28**:25–32.

30 Dawson G, Osterling J. Early intervention in autism. In: Guralnick M, ed. *The effectiveness of early intervention*. Baltimore: Brookes, 1997:307–26.

31 Rogers SJ. Empirically supported comprehensive treatments for young children with autism. *J Clin Child Psychol* 1998;**27**:167–78.

32 Smith B, Chung M, Vostanis P. The path to care in autism: is it any better now? *J Autism Dev Disord* 1994;**24**:551–64.

33 Howlin P, Moore A. Diagnosis in autism: a survey of over 1200 patients in the UK. *Autism: International Journal of Research Practice* 1997;**1**:135–62.

34 Wing L. The handicaps of autistic children. A comparative study. *J Child Psychol Psychiatry* 1969;**10**:1–40.

35 Charman T. Theory of mind and the early diagnosis of autism. In: Baron-Cohen S, Tager-Flusberg H, Cohen D, eds. *Understanding other minds: perspectives from autism and developmental cognitive neuroscience*, 2nd edn. Oxford: Oxford University Press, 2000:427–46.

36 Stone WL. Autism in infancy and early childhood. In: Cohen DJ, Volkmar FR, eds. *Handbook of autism and pervasive developmental disorders*, 2nd edn. New York: Wiley, 1997:266–82.

37 Gillberg C, Ehlers S, Schaumann H, *et al*. Autism under age 3 years: a clinical study of 28 cases referred for autistic symptoms in infancy. *J Child Psychol Psychiatry* 1990;**31**:921–34.

38 Ohta M, Nagai Y, Hara H, Sasaki M. Parental perception of behavioral symptoms in Japanese autistic children. *J Autism Dev Disord* 1987;**17**:549–63.

39 Adrien JL, Perrot A, Sauvage D, *et al*. Early symptoms in autism from family home movies: evaluation and comparison between 1st and 2nd year of life using IBSE scale. *Acta Paedopsychiatr* 1992;**55**:71–5.

40 Osterling J, Dawson G. Early recognition of children with autism: a study of first birthday home video tapes. *J Autism Dev Disord* 1994;**24**:247–59.

41 Baranek GT. Autism during infancy: a retrospective video analysis of sensory-motor and social behaviours at 9–12 months of age. *J Autism Dev Disord* 1999;**25**:355–79.

42 Johnson MH, Siddons F, Frith U, Morton J. Can autism be predicted on the basis of infant screening tests? *Dev Med Child Neurol* 1992;**34**:316–20.

43 Sigman M. The Emanuel Miller Lecture 1997: Change and continuity in the development of children with autism. *J Child Psychol Psychiatry* 1998;**37**:89–126.

44 Mundy P. Joint attention and social-emotional approach behavior in children with autism. *Dev Psychopathol* 1995;**7**:63–82.

45 Charman T, Baron-Cohen S, Swettenham J, *et al*. An experimental investigation of social-cognitive abilities in infants with autism: clinical implications. *Infant Mental Health Journal* 1998;**19**:260–75.

46 Swettenham J, Charman T, Baron-Cohen S, *et al*. The frequency and distribution of spontaneous attention shifts between social and non-social stimuli in autistic, typically-developing and non-autistic developmentally delayed infants. *J Child Psychol Psychiatry* 1998;**39**:747–53.

47 Frankenburg WK, Dodds J, Archer P, *et al*. The Denver II: a major revision and restandardization of the Denver Developmental Screening Test. *Pediatrics* 1992;**89**:91–7.

48 Glascoe FP. *A validation study and the psychometric properties of the BRIGANCE® Screens*. North Billerica, MA: Curriculum Associate, 1996.

49 Ireton H. *Child development inventories*. Minneapolis, MN: Behavioral Science Systems, 1992.

50 Krug DA, Arick J, Almond P. Behaviour checklist for identifying severely handicapped individuals with high levels of autistic behavior. *J Child Psychol Psychiatry* 1980;**21**:221–9.

51 Schopler E, Reichler RJ, DeVellis R, Daly K. Towards objective classification of childhood autism: Childhood Autism Rating Scale (CARS). *J Autism Dev Disord* 1980;**10**:91–103.

52 Adrien JL, Barthelemy C, Perrot A, *et al*. Validity and reliability of the infant behavioral summarized evaluation (IBSE): a rating scale for the assessment of young children with autism and developmental disorders. *J Autism Dev Disord* 1992;**22**:375–94.

53 Lord C, Rutter M, LeCouteur A. Autism Diagnostic Interview–Revised. A revised version of a diagnostic interview for care-givers of individuals with possible pervasive developmental disorders. *J Autism Dev Disord* 1994;**24**:659–85.

54 Lord C, Risi A, DiLavore P, Rutter M. The Autism Diagnostic Observation Schedule–Generic. The Western Psychological Corporation, 1999.

55 Leekam S, Libby S, Wing L, *et al*. Comparison of ICD-10 and Gillberg's criteria for Asperger syndrome. *Autism Int J Res Pract* 2000;**4**:11–28.

56 Siegel B. Detection of autism in the 2nd and 3rd years: the Pervasive Developmental Disorders Screening Test (PDDST). Presentation at the biennial meeting of the Society for Research in Child Development. Albuquerque, NM, April 1999.

57 Berument SK, Rutter M, Lord C, *et al*. Autism screening questionnaire: diagnostic validity. *Br J Psychiatry* 1999;**175**:444–51.

58 Baird G, Charman T, Baron-Cohen S, *et al*. A screening instrument for autism at 18 month of age: a six-year follow-up study. *J Am Acad Child Adolesc Psychiatry* 2000;**39**:694–702.

59 Ehlers S, Gillberg C. The epidemiology of Asperger's syndrome: a total population study. *J Child Psychol Psychiatry* 1993;**34**:1327–50.

60 Ehlers S, Gillberg C, Wing L. A screening questionnaire for Asperger syndrome and other high-functioning autism spectrum disorders in school age children. *J Autism Dev Disord* 1999;**29**:129–41.

61 Attwood T. *Asperger's syndrome: a guide for parents and professionals*. London: Jessica Kingsley, 1998.

62 Baron-Cohen S, Wheewright S, Skinner R, *et al*. The Autism Spectrum Quotient (AQ): evidence from Asperger syndrome/high functioning autism, males females, scientists and mathematicians. *J Autism Dev Disord* 2001;**31**:5–17.

63 Aylward GP. Conceptual issues in developmental screening and assessment. *J Dev Behav Pediatr* 1997;**18**:240–9.

64 Baron-Cohen S, Allen J, Gillberg C. Can autism be detected at 18 months? The needle, the haystack and the CHAT. *Br J Psychiatry* 1992;**138**:839–43.

65 Baron-Cohen S, Cox A, Baird G, *et al*. Psychological markers in the detection of autism in infancy in a large population. *Br J Psychiatry* 1996;**168**:158–63.

66 Robins DL, Fein D, Barton ML, Green JA. The modified Checklist for Autism in Toddlers: an initial study investigating the early detection of autism and pervasive developmental disorders. *J Autism Dev Disord*. In press.

67 Lord C. Follow-up of two-year olds referred for possible autism. *J Child Psychol Psychiatry* 1995;**36**:1365–82.

68 Stone WL, Lee EB, Ashford L, *et al*. Can autism be diagnosed accurately in children under three years? *J Child Psychol Psychiatry* 1999;**40**:216–26.

69 Lord C, Storoschuk S, Rutter M, Pickles A. Using the ADI-R to diagnose autism in preschool children. *Infant Mental Health Journal* 1993;**14**:234–52.

70 Lord C, Pickles A, McLennan J, *et al*. Diagnosing autism. Analysis of data from the Autism Diagnostic interview. *J Autism Dev Disord* 1997;**27**:501–18.

71 Cox A, Klein K, Charman T, *et al*. Autism spectrum disorders at 20 and 42 months of age: stability of clinical and ADI-R diagnosis. *J Child Psychol Psychiatry* 1999;**40**:719–32.

72 Volkmar FR, Cohen DJ. Disintegrative disorder or "late onset" autism. *J Child Psychol Psychiatry* 1989;**30**:717–24.

73 Tuchman RF, Rapin I. Regression in pervasive developmental disorders: seizures and epileptiform electroencephalogram correlates. *Pediatrics* 1997;**99**:560–6.

74 Bristol-Powers MM, Spinella G. Research on screening and diagnosis in autism. *J Autism Dev Disord* 1999;**29**:435–8.

75 Filipek PA, Accardo PL, Baranek GT, *et al*. The screening and diagnosis of autistic spectrum disorders. *J Autism Dev Disord* 1999;**29**:439–84.

76 Filipek PA, Accardo PL, Ashwal S, *et al*. Practice parameter: screening and diagnosis of autism. *Neurology* 2000;**55**:468–79.

77 Hall DMB. Growth monitoring. *Arch Dis Child* 2000;**82**:10–15.

Seizure anticipation

If we had a warning that a seizure was about to happen we might be able to do something to prevent it. Neither clinical observation nor conventional electroencephalography analysis is able to give adequate warning. The standard electroencephalogram (EEG) pattern is either interictal or ictal. Now researchers in France and Belgium (Michel Le Van Quyen and colleagues. *Lancet* 2001;**357**:183–8; see also commentary, Ibid:160–1) have described a preictal phase lasting for several minutes.

The detection of this preictal phase depends on non-linear analysis and the measurement of similarity between segments of the EEG recording distanced in time. Using this technique a preictal phase, detected using intracranial electrode recordings, was described in 1998. The observation has now been extended to standard scalp electrode recordings. Twenty three patients with refractory temporal lobe epilepsy (ages not stated) were studied, 18 using scalp electrodes only and five using both scalp and intracranial electrodes. Twenty six recordings beginning 30–60 minutes before a seizure were analysed and a preictal phase was detected in 25. This phase lasted 1–20 minutes (mean 7 minutes) before the onset of clinical or EEG seizure activity. The findings using scalp and deep electrodes were similar.

More work needs to be done to establish the sensitivity and specificity of these changes and whether they are found in other forms of epilepsy. Nevertheless, the possibilities arise of long term monitoring and preseizure intervention by automated drug administration or intracranial stimulation, or the use of cognitive techniques.

ARCHIVIST