A Model of Early Detection and Diagnosis of Autism Spectrum Disorder in Young Children

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Autism and autism spectrum disorder (ASD) are a group of severe developmental disorders that are characterized by 3 core sets of developmental abnormalities: impairment of social interaction, verbal and nonverbal communication, and restricted, repetitive patterns of behavior. The disorder is far more common than previously thought. There is no cure for autism but it is apparent that early detection followed by early intervention is likely to provide the best chance of long-term beneficial outcome in this condition. Unfortunately, until recently, there had been no validated method of comprehensive early detection of ASD, nor a tool with adequate sensitivity and specificity to be recommended for universal screening of preschool children with ASD. We describe a model of comprehensive early detection and diagnosis of ASD that is achieved by using the resources of primary care workers and a multidisciplinary team with skill and experience in assessing developmental problems in young children and specific expertise in ASD. Both early detection and diagnosis may be carried out by this team in collaboration with parents and primary care professionals and can result in high rates of detection and diagnosis of ASD.

Key words: asperger syndrome, autism, autism spectrum disorder, diagnosis, early detection, early intervention, pervasive developmental disorder not otherwise specified, preschool children, screening

There is general agreement that early detection and early intervention in disease or disability are essential for the long-term benefit of the child and family and also, in the long run, of society (eg, Guralnick, 1997; Keating & Hertzman, 1999; Shonkoff & Meisels, 2000). Parents want to be told at the earliest possible opportunity if there is any concern about their child's development or well-being (Cunningham, Morgan, & McGuken, 1984; Quine & Pahl, 1987). This allows intervention services to be delivered to the child and support provided for the family. Parents are empowered to become knowledgeable about the nature and source of their child's difficulties and plans can be made for appropriate educational intervention for the child. It also enables the family to plan ahead for their future, especially in conditions that have genetic implications. Beside this, it is likely that the window of opportunity to bring about beneficial changes in at least some domains of children's development may be time sensitive (Nelson, 2000). For all these reasons there is increasing emphasis on early identification of developmental problems and institution of appropriate early intervention to maximize the life chances of the child and the family.

These same principles hold true for children with autism and autism spectrum disorder (ASD). Autism and ASD, also known as pervasive developmental disorder (PDD), are a group of severe developmental disorders that are characterized by 3 core sets of developmental abnormalities: impairment of social interaction, verbal and nonverbal communication, and restricted, repetitive patterns of behavior. The disorder is far more common than previously thought. There is no cure for autism but it is apparent that early detection followed by early intervention is likely to provide the best chance of long-term beneficial outcome in this condition. Unfortunately, until recently, there had been no validated method of comprehensive early detection of ASD, nor a tool with adequate sensitivity and specificity to be recommended for universal screening of preschool children with ASD. We describe a model of comprehensive early detection and diagnosis of ASD that is achieved by using the resources of primary care workers and a multidisciplinary team with skill and experience in assessing developmental problems in young children and specific expertise in ASD. Both early detection and diagnosis may be carried out by this team in collaboration with parents and primary care professionals and can result in high rates of detection and diagnosis of ASD. Key words: asperger syndrome, autism, autism spectrum disorder, diagnosis, early detection, early intervention, pervasive developmental disorder not otherwise specified, preschool children, screening.
developmental abnormalities: impairment of social interaction and communication, and restricted and repetitive patterns of behavior and interest (American Psychiatric Association [APA], 1994). The developmental abnormalities manifest themselves early in infancy and may be present from birth. Autism is the most well defined and most intensively researched of all childhood developmental disorders. It is also not as uncommon as was previously thought (Wing & Potter, 2002).

Current best estimates of the prevalence of ASD in children under the age of 8 years is of the order of 60 per 10,000 children (Fombonne, 2003). Autism spectrum disorder can occur in children at all levels of intelligence. However, irrespective of the associated intellectual level, nearly all children with ASD have significant long-term disability. The cause or causes of autism are not known but it is recognized that there is a strong genetic component toward the liability to develop ASD (Rutter, Silberg, O'Connor, & Simonoff, 1999).

There is increasing recognition that early detection followed by early intervention targeting the core developmental deficits is likely to provide the best chance of long-term beneficial outcome for these children (Hoyson, Jamieson, & Strain, 1984; McEachin, Smith, & Lovaaas, 1993; National Research Council, 2001; Rogers & Lewis, 1989). There is therefore an urgency to develop tools and methodologies for early detection and diagnosis of ASD that are prerequisites for the institution of high-quality, evidence-based interventions.

Efforts at devising screening and diagnostic instruments for autism go back a long time. Historically the earliest systematic attempt at this is the Rimland Diagnostic Form for Behavior Disturbed Children, Form E-1. This was rapidly modified and replaced by Form E-2 (Rimland, 1968), which is still available from the Autism Research Institute in San Diego. Rimland's instrument is based on Leo Kanner's original conceptualization of autism that has undergone substantial changes in the intervening years and there are no studies to show how well it fares in diagnosing autism and ASD according to currently accepted diagnostic concepts. Other previous important instruments for screening/diagnosis of autism and ASD are Behavior Rating Instrument for Autistic and Atypical Children (Ruttenberg, Dratman, Frakner, & Wenar, 1966), Handicap, Behavior and Skills schedule (Wing & Gould, 1978), the Behavior Observation Scale (Freeman, Ritvo, Guthrie, et al., 1978), as well as the Autism Behavior Checklist (Krug, Arick, & Almond, 1980) and the highly influential Childhood Autism Rating Scale (Schopler, Reichler, & Renner, 1988).

Of the newer diagnostic instruments that conform to the current ICD-10 (World Health Organization, 1992) and DSM-IV (APA, 1994) diagnostic criteria of autism and ASD (PDD), the most important instruments are the Autism Diagnostic Interview - Revised (ADI-R; Lord, Rutter, & Le Couter, 1994), Autism Diagnostic Observation Schedule-Generic (Lord et al., 2000), and the Diagnostic Interview for Social and Communication Disorders (Wing, Leekam, Libby, Gould, & Larcombe, 2002). The screening instruments for use specifically for very young children are CHAT (Checklist for Autism in Toddlers; Baron-Cohen, Allen, & Gillberg, 1992), Pervasive Developmental Disorder Screening Test (PDDST; Seigel, 1998), Screening Tool for Autism in Two-year-olds (STAT; Stone, Conrod, & Ousley, 2000), and the Modified CHAT (M-CHAT; Robins, Fein, Barton, & Green, 2001). Of these screening tools, CHAT is the most rigorously researched and validated tool for use in very young children. CHAT is designed to screen for autism in children at 18 months of age and was originally used for screening a normal population of 16,235 children. CHAT consists of 2 parts, a parent questionnaire consisting of 9 items and a child practitioner observation schedule consisting of 5 items. Initial research showed CHAT to have very high specificity in identifying cases of autism among young children but subsequent follow-up study has shown that CHAT has poorer sensitivity in identifying less severe cases of ASD (Baird et al., 2000).
The conclusion of the US multidisciplinary consensus panel for screening and diagnosis of ASD on CHAT is that "as a tool for identifying 18-month-olds at risk of autism from a normal population, the CHAT appears to be a useful tool, but not an entirely sufficient tool, for identifying the majority of children who will fall within the autistic spectrum" (Filipek et al., 1999). Nevertheless, apart from its use as a screening tool, CHAT has generated considerable additional benefits in training professionals, raising awareness among primary healthcare workers, and showing for the first time that it is possible to consistently identify children as young as 18 months with autism from a general population of children.

One of the requirements of the successful operation of CHAT screening is the presence of a system of universal surveillance of the general population of young children and a group of primary care workers, such as health visitors, to carry out this surveillance, as is available in the United Kingdom (UK). To overcome the absence of a healthcare visiting professional group to carry out the practitioner observation component of CHAT screening and to maximize the identification of children who show a period of regression between 18 months and 2 years of age, researchers in the United States led by Robins et al. have devised a modified version of CHAT designated M-CHAT. M-CHAT consists of a 23-item parent questionnaire, which incorporates the original 9 items of the CHAT parent questionnaire as well as additional items. The questionnaire takes about 10 minutes to complete and is used purely as a screening instrument and not for diagnosis. Initial results of study using M-CHAT shows excellent sensitivity and specificity (Robins et al., 2001). Further studies are being conducted to determine the usefulness of M-CHAT as a screen in a general population of children.

Another screening questionnaire, PDDST, is also in the format of a parent questionnaire that is available in 3 stages and can be used for different levels of screening from the primary care to the specialist clinic. In initial studies, PDDST shows high sensitivity but moderate specificity (Watson, Baranek, & Di Lavore, 2003) in identifying children with ASD but more work on the use of this tool is continuing.

A further screening instrument, STAT, is an observational tool for use as a second-level screen for children referred with developmental problems. The tool is used by trained observers for children between 2 and 3 years of age in a semistructured play environment to distinguish children with autism from children with other developmental disorders. The test takes about 20 minutes to complete. Preliminary data on sensitivity and specificity of the STAT screen are excellent but work is continuing. Currently apart from CHAT, none of the other tools have been used for population screening of young children with autistic disorder and their performance in this context is not yet known.

In this article, we describe a model of early detection and diagnosis of ASD that is achieved by using the resources of primary care workers, and a multidisciplinary team with experience in assessing children's developmental problem and specific expertise in ASD. A more complete discussion can be found in Chakrabarti and Fombonne (2001), who applied this model in a region in the UK in which 15,500 children were screened. Both early detection and diagnosis may be carried out by this team in collaboration with parents and primary care professionals (Figure 1).

THE APPROACH IN THE UNITED KINGDOM

Stage 1

In the UK, there has been a long tradition of surveillance and screening for medical and developmental problems in young children. The screening and surveillance program is carried out by health visitors, general practitioners (family physicians), and pediatricians. Health visitors in the UK are community-based specialist nurses with general nursing and often midwifery or obstetric training followed by
Stage 1

Universal screening/surveillance of young children
Birth, 6–8 weeks, 6–9 months, 18–24 months, 3½–3½ years
(UK National Recommendation)

Children identified with a developmental problem

Stage 2

Assessment by Child Development Team (CDT)
(Observation of child and elicitation of developmental concerns from parents and referrer)

Problem: Mild/Moderate

a) Mild problem:
   No extra services needed but progress monitored by CDT or referrer.

b) Moderate problem:
   Specific developmental services offered, eg, speech therapy, physiotherapy, early educational intervention, progress monitored by CDT.

Stage 3

Severe or complex problem
Multidisciplinary assessment and medical investigations:
Clinical Diagnosis of ASD

Stage 4

ADI-R & psychometric assessment of children with clinical diagnosis of ASD

Figure 1. Model of screening and diagnosis of ASD in preschool children.

12 months of specific health visiting training and usually wide experience of working with families with young children. A significant component of the health visiting training consists of theoretic and practical aspects of working with families with young children and assessing children’s developmental and physical progress. Health visitors have had a historic and crucial role in health and developmental surveillance, anticipatory guidance, health education, advocacy, and supporting families of very young children in the UK.
The program of surveillance and screening begins with the neonatal examination, followed by periodic assessments at 6 to 8 weeks, 6 to 9 months, 18 to 24 months, and at 3\(\frac{1}{4}\) to 3\(\frac{1}{2}\) years. The neonatal and 6 to 8 weeks' examinations are usually carried out by pediatricians or general practitioners and tend to focus on screening for medical problems, for example, checking for congenital anomalies, heart disease, dislocation of hips, testicular descent in boys, appropriate weight gain, and head circumference, and eliciting any other parental concerns.

The subsequent screening and surveillance are most commonly carried out by the health visitors and consist of a hearing screening at 6 to 9 months and a surveillance program until the age of 3\(\frac{1}{2}\) years. The surveillance is conducted according to the guidelines of the "Health for All Children" report (Hall, 1996), which emphasizes continuity of care, making observations, checking history, eliciting parental concerns, offering health advice and guidance, and moving away from prescriptive tests.

Although there is no total uniformity of practice, on the whole the 2-year and 3\(\frac{1}{2}\)-year health visitor checks tend to have 3 distinct components. The health visitor uses the Personal Child Health Record (PCHR), which is a unique record for each child and is used universally in the UK to record the child's demographic details, birth and medical history, immunization records, and growth and developmental records. The PCHR also contains health promotion and accident prevention advice for parents and parent questionnaires relating to each of the specific developmental stages at 6 to 8 weeks, 7 months, 18 to 24 months, and 3\(\frac{1}{4}\) to 3\(\frac{1}{2}\) years. The parent questionnaire relating to the last 2 time periods, that is, 18 to 24 months and 3\(\frac{1}{4}\) to 3\(\frac{1}{2}\) years, asks parents about their own health, any concern about their child's growth, vision, hearing, speech, understanding, behavior, walking, immunization, and toilet training. The other components of the check are a face-to-face assessment of the child and a dialogue between the health visitor and parents about the result of the check. The direct assessment of the child by the health visitor takes one of various forms. It may involve using a standardized developmental screening tool such as the Denver Developmental Screening Test (DDST; Frankenburg et al., 1992) or a tool called Schedule of Growing Skills (Bellman, Lingam, & Aukett, 1996) or much more likely, using the template of Mary Sheridan's "Children's developmental progress" (Sheridan, 1973). The important point is that, irrespective of the tool being used, it involves engaging the child, face-to-face communication with the child, and using some tasks to briefly look at the child's speech, behavior, social, cognitive, and fine motor skills. The check takes about 30 minutes to complete and is carried out at the local clinic or at home, depending on individual preference and local guidance. The dialogue with parents at the end of the assessment would include a discussion of any concerns raised in the parent questionnaire that parents would have already filled in or filled jointly with the health visitor. On the basis of this information and the result of the direct assessment, the parents and the health visitor would arrive at an agreed decision about any further course of action if any problem is identified.

The popularity and general acceptance of these surveillance measures is shown by the fact that in our area the uptake rate of the 2-year check is 82% and that of the 3\(\frac{1}{2}\)-year check is 79% of all eligible children. These are clearly high figures in any general population surveillance.

Apart from these scheduled screening and surveillance, the health visitor often has more ongoing contact with families who have more than 1 young child and also families where an earlier problem or potential problem had been identified. For example, health visitors would provide closer support and monitoring for mothers with postnatal depression, families lacking adequate social support, or parents who have learning or mental health problem, or there are child protection concerns or
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a child is born prematurely or has a medical problem.

The health visitor is also available to listen to, and offer advice about, any specific worries or concerns parents have about their child outside the scheduled program of contacts, and especially during the nationally recommended immunization sessions when the children are 2, 3, 4, and 13 months and 3 years old. Two other groups of professionals, apart from the health visitors, are known to be closely involved with young preschool children with actual or potential developmental problems, namely, pediatricians and speech and language therapists. As described below, these 3 professional groups, that is, health visitors, pediatricians, and speech and language therapists, were targeted as the most likely sources of referral of very young children with atypical development and in particular of children with potential ASD.

To establish our model, we approached these prospective referrers and arranged for brief training sessions on early identification and referral of developmental problems. We also provided written guidelines for referral. The training program and guidance took the form of publicizing the services available at the Child Development Center, the different and complementary mix of expertise available to assess young children's development, the rationale and urgency of early referral of children who are thought to have developmental concerns, and discussion about guidelines for referral.

The guidance for the referrals was left purposefully general and wide to provide maximum sensitivity for ASD case finding. We hypothesized that children with ASD, even the ones with normal or superior intelligence, would show some forms of atypical development, if not delay as well, and felt that it was crucial to cast a wide net to find these children. However, we were also anxious not to get overwhelmed with lots of children with minor or transient developmental delays.

To achieve this dual aim, the suggested criteria for initial referrals were to include any child with moderate to severe impairment in one area of development or mild or moderate impairment in 2 or more areas. Any impairment that in the clinical judgment of the primary care worker and/or parents was thought to be more than transient was considered as significant (moderate or severe, according to the judgment of the referrer). The areas of development comprised motor development, speech and language development, socialization and play, behavior, vision, and hearing. The referrers were also advised to refer any child about whom either parents or professionals had concern, although the concern could not be described in more specific developmental terms. We put extra emphasis on concerns expressed by parents as well as on professional's clinical judgment, irrespective of the results of any screening test used.

Referrals were sought as soon as any problem was identified but tended to cluster around the specified ages of developmental surveillance, mostly around the age of 2 and 3 years. All referrals were made with parents' consent.

Stage 2

All parents along with their children referred at this initial stage were invited to a brief meeting lasting about half an hour with a child development team. The team consisted of a pediatrician, a health visitor, speech and language therapist, physical, occupational, and play therapist. The primary referrer, frequently a health visitor or speech therapist, who knew the parents and the children well, often attended the meeting as well. This was found to be very helpful for parents and professionals alike. Every effort was made to encourage the parents to attend the meetings, the family health visitor often being instrumental in helping parents in hard-to-reach families. During the meeting there was opportunity to observe the child informally in brief play, encouraged by the play therapist, whereas the team explored the parents' and
the referrer's concerns about the strengths and weaknesses of the child's development. At the end of the meeting, taking the parents' views and all the information into account, a joint agreement was reached between the parents and the team that the child's progress was such that

a. no extra services were warranted for the child's optimal development but the child's progress needed monitoring or
b. specific developmental services such as speech therapy, physical therapy, or occupational therapy and/or early educational intervention and close monitoring of the child's development were necessary or
c. the nature and/or extent of the child's developmental problems were such that a further, more in-depth assessment of the child's development was required.

For children in pathways a and b, options remained open for more in-depth assessment at a later date if on follow-up, this was thought necessary and helpful for the child and family.

Stage 3

The children who were selected for in-depth assessment attended the local child development center in groups of 4 children for a period of 2 weeks. The composition of each group remained constant during the assessment period and groups of 4 children were assessed consecutively at 2-week intervals. The assessments were conducted by a multidisciplinary team of professionals and spread over 10 daily sessions of 2 hours each. During the assessment, a play therapist led the group of 4 children with their participating parents in structured activities as well as in free play in a specifically built nursery environment. Parents were invited to be with their children during these sessions. Most children were accompanied by their mothers but a significant number of fathers also attended at least some of the sessions. The children were grouped so as to be fairly close in age range to each other, mostly between the ages of 2 and 3 years, with an occasional child below the age of 2 or above the age of 4 years.

During play sessions, a particular note was taken of the children's behavior, social skills, and interaction with the peer group and adults. Note was also made of the children's speech and communication in a more naturalistic setting than a formal individual assessment session. The children were observed for their motor skills, attention, listening, and distractibility. Any unusual behaviors, particularly unusual sensory behavior (showing distress or covering ears with hands to block out noise or peering at objects through corner of eyes), repetitive behaviors, or stereotypies (hand flapping, tiptoeing, etc), were recorded.

A developmental pediatrician experienced in ASD took a detailed developmental history and conducted a comprehensive medical and neurodevelopmental examination. All children had appropriate biologic investigations according to a standard protocol. Children were assessed by a speech and language therapist experienced in assessing children with ASD and other learning and developmental problems. The children's gross and fine motor skills were assessed by a physical therapist and an occupational therapist, respectively. The children were also observed and parents interviewed by a specialist nurse in behavior intervention, with wide experience of working with children and families with ASD.

The children's hearing was tested by an audiolgic physician and vision screened by an orthoptist. A dietician and nutritionist took a detailed dietary history of the children and obtained a 3-day food diary from the parents for an analysis of the adequacy of the diet with respect to intakes of calorie, vitamins, and micronutrients, compared to the recommended reference nutritional intakes of a child of similar age. The children's teeth and oral hygiene were inspected by a dental nurse.

All families had a general interview with a social worker who subsequently took up
follow-on work with individual families to access social care and statutory benefits as appropriate and needed by the child and family. At the end of the 2-week period of assessment, all the results were collated by the lead pediatrician and a clinical diagnostic formulation of the child’s problem was made.

Stage 4

Children who were strongly suspected to have ASD underwent further assessment with a standardized diagnostic measure, the Autism Diagnostic Interview-Revised (ADI-R), and a psychometric assessment, using the Wechsler Preschool and Primary Scale of Intelligence (WPPSI; Wechsler, 1990) or Merrill Palmer Scale (Stutsman, 1948).

The ADI-R is a semistructured diagnostic interview for use with the parents or main caregivers of the child with possible ASD diagnosis. The ADI-R algorithm generates scores for areas of social interaction, communication (verbal and nonverbal), and repetitive behavior for which appropriate cutoff points for diagnosis are available. The ADI-R algorithm is compatible with the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV), and International Classification of Diseases, 10th edition (ICD-10), diagnostic criteria.

All but a few children with ASD had a formal psychometric assessment. As children with ASD vary enormously in their intellectual and verbal ability, 2 specific instruments were used for psychometric testing. The WPPSI was used for verbal children and Merrill Palmer Scale was used for nonverbal children.

OUTCOMES OF THE SCREENING PROGRAM

Detailed results and their likely interpretation are available in Chakrabarti and Fombonne (2001). In brief, of the 576 children referred to the Child Development Center following stage 1 assessment, 97 children were diagnosed with PDD (ASD) at the completion of stage 4, resulting in a prevalence estimate of 62.6 (95% CI, 50.8–76.3) per 10,000 children for all PDDs (ASDs). Of the 97 children, 26 were diagnosed with autistic disorder (16.8 per 10,000), 13 with Asperger syndrome (8.4 per 10000), 1 girl with Rett syndrome, 1 boy with childhood disintegrative disorder, and 56 children with PDDNOS (36.1 per 10000).

Of the 97 children with PDD, 34% of the children were referred by pediatricians, 32.9% by speech and language therapists, 21.6% by health visitors, and 5.1% by family physicians (general practitioner in the UK), and 6.2% were from various other sources. However, closer inspection of the referral pattern showed that most of the referrals to pediatricians and speech therapists were initiated by health visitors. Taking these data into account, it was estimated that 79 (81%) of the 97 children were originally identified by health visitors as children with a developmental problem requiring further assessment.

The average age of referral of the children was 35.7 months (range, 11–63 months), and average age at initial diagnosis was 41 months (range, 21–78 months). A statistically significant difference was found in both age of referral and age of diagnosis depending on diagnostic category. Children with autism were referred (mean age of referral, 30 months) and diagnosed (mean age of diagnosis, 34.6 months) earlier than children with PDDNOS (mean age of referral, 37.2 months; mean age of diagnosis, 43.1 months) who, in turn, were referred and diagnosed earlier than children with Asperger syndrome (mean age of referral, 47.5 months; mean age of diagnosis, 51.8 months).

Of the 97 children, 77 were boys (79.4%) and 20 girls (20.6%). Ninety-three of the 97 children were administered psychometric assessment. Of these, 24 children (25.8%) had some degree of mental retardation.

IMPLICATIONS FOR PRACTICE

In this article, we have described a model of detection and diagnosis of autism and
ASD in young children (children between 2 and 4 years of age) which has been used in the UK context. The model we have described is broadly in line with the main recommendation of the consensus panel (Filipek et al., 1999) on screening and diagnosis of autism except the use of an autism-specific screening instrument. We feel that the currently used ASD screening instruments may be too restrictive in identifying the broad range of autistic disorders in young children.

Understandably, the common target of all ASD screening instruments is the identification of autism-specific behaviors and developmental patterns in children. Although there is extensive information and broad agreement about the presentation, range of behavior, and developmental patterns of children with autism, there is much less research and information about the antecedents of children with eventual diagnosis of milder variants of ASD such as PDDNOS (pervasive developmental disorder not otherwise specified) or Asperger syndrome. Because of this, we felt that it is important not to assume that these children with ASDs, but not autism disorders, would also present with behavioral features that have been commonly targeted in autism screening instruments. On the contrary, our view is that it is important to keep a broader perspective and target any atypical development in children as subjects of interest.

A further difficulty in consistent and comprehensive detection and diagnosis of ASD is that despite the overall prevalence of the condition being much higher than previously thought, it is nevertheless a small proportion of all children whose development may cause some concern. It is estimated that 12% to 16% of all children present with some developmental or behavioral difficulty (Boyle, Decoufle, & Yeargin-Allsopp, 1994). Of these children, only about 4% to 5% would be expected to have an ASD. Hence, searching for children with ASD is like the proverbial search for a needle in a haystack, although it is a larger needle than previously thought.

Autism spectrum disorder may occur in children of all social classes and economic and demographic backgrounds. Apart from a small number of recognized medical conditions (tuberous sclerosis, Fragile X syndrome, etc) and siblings of index cases of ASD, there are no other known risk factors that can be targeted and lend themselves to selective screening.

As a consequence, effective strategies for general population screening are necessary to identify all cases of ASD. We have shown that with uptake rates of around 80%, the health visitor young child surveillance provides an ideal opportunity to sample preschool children's developmental progress over a course of time. It also must be remembered that apart from the scheduled surveillance, the health visitor also carries out some opportunistic surveillance, particularly in hard-to-reach families, and these may not be counted in the statistical record of the surveillance figures. We are reasonably confident that the true uptake of the surveillance is higher than the recorded figures.

The other important aspect of the surveillance is that the process is repeated to sample 2 crucial ages in the children's early development, at 2 years and 3½ years. In our experience, repeated sampling of children's development over a course of time during children's early development is crucial to maximize case finding in ASD. In children subsequently diagnosed with ASD, parents often recognize that "something is not right in their children's development" by the age of 18 and 20 months (Di Giacomo & Fombonne, 1998). However, this is by no means universal and there are children with ASD whose development does not arouse concern in their parents until the age of 2 or 3 or even 4 years. Screening instruments designed for use at single age points are likely to miss these children.

One of the criticisms of the feasibility of our model is that it is dependent on a professional group like health visitors for initial detection of children with developmental problems. Without the health visitors the
success of the model would be compromised. However we would suggest that in countries without the tradition of a health visiting profession, the task of identifying children with developmental problem would fall on other primary care workers, be it pediatricians, family physicians who look after children, play group leaders, nursery or kindergarten teachers, or children's early intervention professionals.

There is now a whole range of validated, high-quality screening instruments including Parents' Evaluations of Developmental Status (Glascoe, 1998) for primary identification of developmental and behavioral problem in young children. These could possibly take the place of health visitor screening. Whether the uptake rates and outcomes from these screens would be comparable to the screening we described remains to be seen. There may also be some concern that the suggested 2-week multidisciplinary assessment in our model is too long for parents to be able to afford, particularly in countries where both parents are more likely to be working. The model may also be thought to be expensive in professional time and resources.

On the question of parent participation, we find it invaluable to arrive at an informed, shared understanding of the child which parents are comfortable with if at least 1 parent is present during the assessment. This is because the parents actively participate in the assessment process and have a continuous dialogue with the professionals so that the outcome of the assessment is not a rude surprise. When the parents are already attuned to a diagnostic possibility of an ASD, it is easier for parents to identify and become more knowledgeable about the strengths and developmental problems of their child during the assessment. However, as pointed out by Charman and Baird (2002), "the difficulties of recognition, belief and acceptance are far from easy when the professional is giving completely unexpected information." In these cases, parents tell us that they find the 2-week assessment extremely helpful to attune themselves and come to some understanding as to what it is in their child's development that is causing concern.

Although we welcome both parents and grandparents if they share the child's care and sometimes siblings, it is mostly mothers who attend all the sessions. In our experience it is extremely rare for parents to decline or withdraw from an assessment. Regarding the cost of the model, we feel that it is likely to be more than compensated in financial term by the cost saving in better outcomes for the child and family (due to early intervention) and less dependence on costly services from the state. More than this, the savings in human terms in reducing frustration and anguish of both parents and child and interminable wait for parents to come to an understanding of their children's difficulties may themselves be very significant. This is also what parents want (Howlin & Moore, 1997).

On all these counts, we feel that our model has much to commend itself for comprehensive early detection and diagnosis of autism and ASD.

REFERENCES


