



A new screening programme for autism in a general population of Swedish toddlers

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ABSTRACT

The evidence from early intervention studies of autism has emphasised the need for early diagnosis. Insight into the early presentation of autism is crucial for early recognition, and routine screening can optimise the possibility for early diagnosis. General population screening was conducted for 2.5-year-old children at child health centres in Gothenburg, Sweden, and the efficacy of the screening instruments in predicting a clinical diagnosis of autism was studied. The tools used for autism screening comprised the Modified Checklist for Autism in Children (M-CHAT) and an observation made by trained nurses of the child's joint attention abilities (JA-OBS). From the new screening procedure a "definitive" suspicion of autism spectrum disorder (ASD) was raised in 64 individuals in the study population of 3999 young children. Fifty-four of these were clinically assessed in detail. Forty-eight children had a confirmed diagnosis of ASD, three had severe language disorder, and three (6%) were classified as having typical development. The *Positive Predictive Value (PPV)* for the combination of M-CHAT and the JA-OBS was 90%. The combination of instruments used showed promise for early detection of autism as a routine in the developmental programme at child health centres. Trained medical staff is a basic requirement and enables earlier detection and the use of screening tools beyond routine population screening regardless of the age at which a suspicion of autism is raised.

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1. Introduction

In autism, in the vast majority of cases, symptoms are present from the first two years of life, but there is still often a considerable delay before the diagnosis of autism is made. The rationale for early autism screening is the evidence that early intervention is helpful in improving developmental functioning and reducing symptoms (Dawson et al., 2010; Howlin, Magiati, & Charman, 2009; Ospina et al., 2008; Rogers & Vismara, 2008). Although there is much controversy regarding different intervention approaches, and no specific treatment for all symptoms and for all children exists, the available evidence underscores the importance of early detection and intervention for toddlers with autism.

In most western countries there are developmental child health programmes for children from their first months of life. In Gothenburg, a metropolitan area on the Swedish west-coast, 95–99% of children are followed up at the child health centres (CHCs) during their first years (Arvidsson, Holmberg, Reuter, & Strömbom, 2010). Despite regular health check-ups, in recent

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years, the symptoms of autism have not been noticed, or if noticed not led to referral for autism diagnostic assessment until several years later (Nygren et al., 2011). The observed delay in diagnosis was the background for a collaborative project for early detection, diagnosis and early interventions for young children with autism spectrum disorders in Gothenburg. In the following we will present methods for screening and early detection of autism.

The knowledge about early autism symptoms comes from at least three sources; (1) retrospective studies of symptoms in children who later got the diagnosis of autism and (2) prospective studies of high-risk children (siblings of children with autism) who have been followed up from birth and (3) combined retrospective prospective controlled studies comparing infancy video-tapes of individuals with and without a later diagnosis of autism, atypical autism or Asperger syndrome (Baron-Cohen, Allen, & Gillberg, 1992; Gillberg et al., 1990; Robins, Fein, Barton, & Green, 2001; Werner, Dawson, Munson, & Osterling, 2005). The symptoms that have been noted have often been related to lack or deficiency of joint attention skills, an ability that is crucial for development of social communication (Lawton & Kasari, 2011; Mundy, Sullivan, & Mastergeorge, 2009). Other early possible autism symptoms are motor difficulties, perceptual-sensory problems, stereotyped play with objects and fixation on objects. Early sleeping and feeding problems are also common (Dahlgren & Gillberg, 1989; Dawson, 2011; Teitelbaum, Teitelbaum, Nye, Fryman, & Maurer, 1998). Some children exhibit autism symptoms early during the first year, but more consistently around 12 months. Although there is individual variability at many levels in the heterogeneous autism spectrum, several symptoms are often present by the age of 18 months (Bryson et al., 2007; Kleinman, Robins, et al., 2008).

The choice of point for *population screening* is related to knowledge about the validity of neurodevelopmental diagnosis in young children. Children with autism share many symptoms with children with other types of developmental delays, including those with general developmental delay and developmental language delay. There is often also an overlap (or “comorbidity”) between diagnoses such as autism and general developmental delay in young children. The social characteristics in young children with ASD have been compared to those of children with other developmental problems (Ventola et al., 2007). Children with ASD have been found to be more impaired in joint attention, imitation skills, pointing to express interest, interest in other children, empathic responding and in range of facial expressions (Lord, 1995; Rogers, Hepburn, & Wehner, 2003; Trillingsgaard, Ulsted Sorensen, Nemeč, & Jorgensen, 2005). Children with autism also appear to have a specific pattern of impairments in communication, including fewer conventional gestures, and they may be less likely to initiate and respond to verbal communication (Lord, 1995; Trillingsgaard et al., 2005). Other studies have shown that children with autism have significantly less pretend play than children with other disabilities (Cox et al., 1999; Noterdaeme, Sitter, Mildnerberger, & Amorosa, 2000). Several longitudinal studies have shown that the diagnosis of autism made around the age of 2–4 years is relatively stable over time (Gillberg et al., 1990; Kleinman, Ventola, et al., 2008; Lord, 1995; Lord, Risi, DiLavore, Shulman, Thurm, & Pickles, 2006). There is, internationally, a quest for very early screening, including during the first year. Still, the evidence for population screening of children under age 2 years remains meager (Al-Qabandi, Gorter, & Rosenbaum, 2011; Baron-Cohen et al., 1992; Pandey et al., 2008; Willemsen-Swinkels, Buitelaar, & van Engeland, 2001).

2. Aim

The primary aim of the Gothenburg study was to develop and review an autism screening procedure within the existing developmental surveillance programme at the CHCs. A secondary aim included assessment of the psychometric properties of the screening tools. It is this secondary aim that is the focus of the present paper.

3. Material and methods

The autism population screening was conducted at all the CHCs in Gothenburg during the entire year of 2010. The screening was the first part of a three-wave collaborative “Autism: Detection and Intervention in the Early years (AUDIE)” project which had started in 2009 in Gothenburg. The second wave of the project comprised diagnostic assessments and diagnostics at the Child Neuropsychiatry Clinic (CNC) at the Queen Silvia Children’s Hospital, serving the whole of Gothenburg, and to which the children were referred if screening had raised any suspicion of ASD (see Nygren et al., 2011 for details about the extremely detailed assessments, comprising the Autism Diagnostic Schedule (ADOS) (Lord et al., 2000). The Diagnostic Interview for Social and Communication disorders (DISCO-11) (Nygren, Hagberg, Billstedt, Skoglund, Gillberg, & Johansson, 2009; Wing, Leekam, Libby, Gould, & Locombe, 2002) and cognitive assessment among other things in accordance with a structural protocol in all cases). The ASD category comprised DSM-IV/ICD-10 autistic disorder/childhood autism and DSM-IV/ICD-10 PDD-NOS/atypical autism. In the third wave of the project all parents of children with a confirmed diagnosis of autism spectrum disorders were offered early interventions for their children at the habilitation service centres. Clear routines were established as to how to guarantee care efficacy. The goal was to complete the diagnostic assessment within 4 months from the date of raising the suspicion of ASD at the CHC and for multimodal interventions to be provided after the diagnosis without delay.

3.1. Study population

The total population in the city of Gothenburg was 513 751 on December 31 2010. The study population consisted of children, born in 2007 or 2008, coming for their 2.5-year-old *check-up* at the CHCs at any time during 2010. The 2.5-year-old

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