



Preschoolers assessed for autism: Parent and teacher experiences of the diagnostic process



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ABSTRACT

Many parents of young children with autism spectrum disorder (ASD) have often been recommended to “wait and see” when they have first expressed concerns. This comparative, descriptive, partly longitudinal questionnaire study aimed to evaluate parent/preschool teacher experiences as regards time of first concern about the child and about the diagnostic process at a specialized Child Neuropsychiatry Clinic. Participants were parents and teachers of 34 preschool children with suspected ASD (26 boys, 8 girls, mean age 37 months) drawn from a general population cohort. Most of the parents, and the teachers, had their first concern about the child’s development before the child’s second birthday. Generally, they were satisfied with the diagnostic process and did not regret their participation in it.

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1. Introduction

Research into early interventions for young children with autism spectrum disorder (ASD) and other developmental disabilities has flourished in the past decade (Eikeseth, 2009; Gillberg, 2010; Rogers & Vismara, 2008). There has also been increasing focus on the importance of clinical assessment of other preschool children with Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations (ESSENCE) (Gillberg, 2010), and, on the need for multidisciplinary information in the assessment process (Charman & Baird, 2002; Steiner, Goldsmith, Snow, & Chawarska, 2011). The ESSENCE concept draws attention to comorbidity in neurodevelopmental disorders and the importance of identifying all early symptoms of developmental disorders in young children (not just those associated with a particular circumscribed diagnostic category such as “ASD”, “ADHD” or “language delay”), offer interventions and make follow-up evaluations a few years later.

Recent ASD studies of parents’ first concerns about their child’s early development indicate that worries often begin when the child is 12–24 months of age (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011; Ozonoff et al., 2009; Ryan & Salisbury, 2012; Siklos & Kerns, 2007), but later and earlier concerns have also been reported. Parent’s first concerns for children later diagnosed with ASD have been reported to be earlier for girls than boys (Horovitz, Matson, Turygin, & Beighley, 2012), but studies in this area have been very few. There are more boys than girls diagnosed with ASD, and gender differences concerning symptoms have been reported (Kopp, Kelly, & Gillberg, 2010; Mandy et al., 2012). However, in a recent study of preschool boys and girls from the general population, diagnosed with ASD, matched for age and developmental level, no

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significant differences were found between girls and boys in respect of clinical presentation or developmental profiles (Andersson, Gillberg, & Miniscalco, 2013), even though this could have been caused by only the most “severe” girl cases had been recognized at this young age.

Parental stress caused by their child’s developmental problems, especially ASD, has been described in several studies (Estes et al., 2013; Pottie & Ingram, 2008; Schieve, Blumberg, Rice, Visser, & Boyle, 2007). A recent review of the family impact of ASD (Karst & Van Hecke, 2012) reported that the child’s behavioral problems appeared to be related to parental stress, but also to parental concern about raising the child, and to financial strains. There are high rates of divorce in parents of children with ASD. Stressful and strained family situations have been shown to occur regardless of the severity of the child’s problems (Pottie & Ingram, 2008). In the case of siblings, both positive and negative outcomes have been reported and family and individual factors have been suggested to be more important for outcome than the consequences of the disorder itself (Green, 2013).

Higher degrees of stress have been reported in parents of young children with ASD compared to parents of same-aged children with developmental delay without ASD (Karst & Van Hecke, 2012). Parental stress has also been suggested to reduce the effectiveness of early interventions (Osborne, McHugh, Saunders, & Reed, 2008). Also, frustration and concerns associated with problems obtaining an early diagnosis have been reported (Mansell & Morris, 2004). In addition, parents have experienced the diagnostic process as more negative, if the waiting time for assessment has been long (Howlin & Moorf, 1997).

Information during the diagnostic process is suggested to be important and most parents tend to prefer a quick and structured diagnostic process (Chamak et al., 2011; Osborne & Reed, 2008; Reed & Osborne, 2012). Previous research has suggested that many parents are unsatisfied with the (long) time period of the assessment process, and that the diagnostic information during the process has been too limited (Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010). These findings would suggest the need for better routines and more focus on parental sense of security and participation in the assessment process, and on the planning of interventions. Keeping the family context and individualization of interventions in focus appears to be important for positive outcomes as regards family functioning (Ylvén, Björck-Åkesson, & Granlund, 2006). A well functioning family can impact on the child’s positive development (Green et al., 2010; Muratori & Narzisi, 2014; Reed & Osborne, 2012). Given that, in many instances, parents are faced with a difficult situation with their young child with ASD, it is important to obtain first-hand knowledge about parental experience in order to be able to provide good care for the whole family in the diagnostic process.

In Sweden, most children attend preschool from 1 to 2 years of age. This means that the teachers in the preschools have the possibility of identifying problems early in the child’s life. A newly published study from Gothenburg, Sweden, showed that ASD-observation for diagnosis in preschool yielded very similar results as did corresponding observation in a specialized clinic (Westman Andersson, Miniscalco, Johansson, & Gillberg, 2013a). In addition, first clinical impression by an ASD-experienced education specialist in connection with preschool observation, showed good agreement with final comprehensive clinical diagnosis (Westman Andersson, Miniscalco, & Gillberg, 2013). These findings suggest that it is important to obtain information from preschool teachers about the child with suspected ASD and about how she/he handles a number of everyday life situations. Given that the child spends several hours a day in the preschool, it is also important that teachers get information about the diagnosis and its implication, when the ASD-assessment has been completed. Such information should provide teachers with tools to support the child and provide early interventions, which have been suggested to be important for the child’s positive development (Eikeseth, 2009; Klintwall, Gillberg, Bolte, & Fernell, 2012; Rogers & Vismara, 2008).

The present study was undertaken in the context of a general population screening for ASD in preschool children. We wanted to (1) determine at what child age the parents had first been concerned; (2) assess parental experience of the neuropsychiatric diagnostic process; (3) obtain similar information from preschool teachers; (4) analyze to what extent the level of child problems affected responses from parents and teachers, and (5) study possible child gender differences.

2. Methods

2.1. Study design

This is a comparative, descriptive, partly longitudinal questionnaire study of parent and teacher experience of the ASD diagnostic process. Comparisons were made between parent and teacher responses across gender and autism severity. The parents were invited to complete the questionnaire twice, with a one-year interval and the answers from these two time-points were compared.

2.2. Participants

Parents and teachers of 34 children (26 boys, 8 girls, age range 23–47 months, mean age 37 months), consecutively recruited in the framework of the broader population-based Autism Diagnosis and Intervention in Early life (AUDIE) study (Kantzer, Fernell, Gillberg, & Miniscalco, 2013; Nygren et al., 2012) and referred for suspected ASD (after general population screening for ASD/language problems) to the Child Neuropsychiatry Clinic (CNC) in Gothenburg, Sweden, were included in the study and were invited to complete questionnaires. All the parents who had agreed to participate in the AUDIE project during a limited time period were selected for inclusion. Initially, 50 families were targeted, but 12 had to be excluded because none of the parents were able to read Swedish, and so were unable to complete the questionnaires without the help

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