

Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders

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Abstract

Although no Canadian studies have been conducted, studies suggest parents of children with autism experience difficulties obtaining a diagnosis for their child. Fifty-six parents of children with autism completed three questionnaires providing information on the families' demographics, parents' experiences throughout the diagnostic process, and their child's autistic symptomatology. These parents experienced significant difficulties obtaining a diagnosis for their child. Parents saw an average of 4.5 professionals, and waited almost 3 years to receive a diagnosis following their first visit to a professional regarding their child's development. The impact of autistic symptomatology on the diagnostic process is discussed.

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1. Introduction

Autism, which was first described by Kanner (1943) more than half a century ago, is a severe developmental disability affecting approximately 5 out of 10,000 individuals, and is three to four times more common in boys than girls (*Diagnostic and statistical manual* (4th ed., text revision) [DSM-IV-TR]; American Psychiatric Association, 2000). The DSM-IV-TR (American Psychiatric Association, 2000) now classifies autism as a pervasive developmental disorder (PDD), defined by abnormal development in social interaction, impairments in communication, and a restricted repertoire of interests and activities. The term "autism spectrum disorders (ASD)" (Wing, 1988) will be used throughout this paper, and should be considered interchangeable with the term pervasive developmental disorders used in DSM-IV-TR. It will be

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used to represent individuals with autistic disorder, Asperger's syndrome, and pervasive developmental disorder-not otherwise specified.

Despite the fact that the symptoms of ASD can often be detected in a child as young as 12–18 months of age (Baghdadli, Picot, Pascal, Pry, & Aussilloux, 2003; Howlin & Asgharian, 1999; Osterling & Dawson, 1994; Osterling, Dawson, & Munson, 2002), and can be reliably diagnosed by the age of 30 months (Gillberg, Norden, & Ehlers, 1996), on average, the diagnosis does not take place until the child is approximately 5–6 years of age (Howlin & Moore, 1997). The delay in providing early diagnosis may be due to: (1) the variability in the nature and development of autism in different children; (2) the limitations of the assessment itself, including scarcity of assessment measures suitable for use with preschool age children, limited time available for the assessment, no assessment across time or in a range of difference environments, and strong reliance on parent reports; (3) a lack of specialized training among professionals to recognize the early subtle symptoms of ASD; (4) a shortage of specialized services (Chung, Smith, & Vostanis, 1995; Kabot, Masi, & Segal, 2003; Selfe, 2002). Still, the early detection and diagnosis of ASD in young children is essential for providing services, developing a treatment plan, and for preparing the parents to adapt to a child with a disability by helping them to obtain information and access appropriate services (Chung et al., 1995; Konstantareas, 1990, 1989; Nissenbaum, Tollefson, & Reese, 2002; Siegel, 1996). Early diagnosis is also essential for implementing early interventions known to have a positive effect on later outcome.

1.1. Satisfaction with the diagnostic process

A positive experience within the diagnostic process has a significant impact on a parent's initial reaction to the diagnosis of a developmental disability (Cottrell & Summers, 1990; Leff & Walizer, 1992; Quine & Pahl, 1986; Stallard & Lenton, 1992; Woolley, Stein, Forrest, & Baum, 1989). In spite of the importance of a positive diagnostic experience, many parents of children with ASD remain dissatisfied with this process (Howlin & Moore, 1997; Smith, Chung, & Vostanis, 1994). Howlin and Moore (1997) conducted a survey of over 1200 families belonging to autism support groups in the United Kingdom, in which parents were asked about their experiences in obtaining a diagnosis for their child. They found that: (1) parents who had received an early diagnosis were more satisfied with the diagnostic process than those who had to wait longer; (2) parents who had received a clear-cut diagnosis of autism or Asperger syndrome were more satisfied with the diagnostic process than those receiving a more vague diagnosis of autistic "traits," "features," or "tendencies;" (3) abnormalities in communication were the principal initial source of concern for the majority (40%) of parents, and just under 20% were initially anxious about their child's social development; (4) diagnosis was made earlier for the younger children in the survey, suggesting that children are beginning to be diagnosed at younger ages though "years since the diagnosis was made" was not controlled for, and therefore, it is not possible to conclude that diagnoses are in fact occurring at younger ages. These researchers also found that parents needed to persist to obtain a diagnosis for their child: only 8% received a formal diagnosis upon their first visit with a professional, only 40% received the diagnosis after a referral to see a second professional, and the majority, 63% obtained a diagnosis for their child only after their third visit with a professional. Howlin and Moore (1997) reported that 49% of the parents surveyed were "not very" or "not at all" satisfied with the diagnostic process indicating that parents' attempts to obtain a diagnosis for their child are laden with delays and frustrations.

In summary, the literature clearly indicates that parents of children with ASD experience significant hardships in attempting to obtain a diagnosis for their child. Parents typically are first

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