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A possible contra-indication for early diagnosis of Autistic Spectrum Conditions: Impact on parenting stress

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ABSTRACT

The current study investigated the impact of diagnosis of Autistic Spectrum Conditions (ASCs) in children on parenting stress. While there is increasing pressure to provide early diagnosis of ASC, there is a lack of evidence relating to the impact of early diagnosis on the parents. The parents of 85 children with ASC completed measures of their parenting stress, and gave a brief history of their child and their diagnosis. The children were assessed for autistic severity and behavioral functioning. Autistic severity predicted their parents' first noticing a problem, and the speed of the latter, rather than the child's autistic severity, predicted obtaining an earlier diagnosis. The autistic severity of a child was related directly to parenting stress. However, earlier diagnosis may be detrimental to levels of parenting stress. While parenting stress declined over time from the point at which the parents had first noticed a problem in their child, it failed to change by any significant degree once the diagnosis of ASC had been received. Given this possible contra-indication for early diagnosis of ASC, it warrants caution and further investigation.

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Early diagnosis is a common goal in the management of many conditions, and the associated early treatment leads to enhanced outcomes, and better long-term prognosis. The same is true for the diagnosis of Autistic Spectrum Conditions (ASCs) in children. It is often suggested that intervention for ASC is more effective if offered early, rather than remedially later (Lovaas, 1987), and such suggestions produce pressure for earlier diagnosis of the condition. Certainly, an early diagnosis of ASC can

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facilitate access to services (Gillman, Heyman, & Swain, 2000), and would seem to enhance the treatment prognosis for the child.

However, while there may well be benefits of an early diagnosis for the child with ASC, it is known that the diagnosis of mental problems can have dichotomous and paradoxical effects. For example, people diagnosed with schizophrenia can have poorer probability of remission than those with no such label (Bentall, 1990). In pediatric cases, such as ASC, the impact of diagnosis is also often seen in the parents. For example, the diagnostic processes concerning ASC can produce extreme levels of stress in the parents (Goin-Kochel, Mackintosh, & Myers, 2006; Osborne & Reed, 2008). It is known that high levels of stress in the parents can have detrimental impacts on the children, in terms of treatment outcomes (e.g., Osborne, McHugh, Saunders, & Reed, 2008a; Robbins, Dunlap, & Plenis, 1991), and behavior problems (e.g., Lecavalier, Leone, & Wiltz, 2006). Given the above, the current report sought to explore whether there were any potentially detrimental aspects of the diagnosis of ASC for the parents of the diagnosed child, and to try to tentatively identify the predictors of any adverse parental reactions.

It appeared important to focus on parenting stress for a number of reasons. In terms of treatment outcomes for children with ASC, Robbins et al. (1991; see also Osborne et al., 2008a) noted a strong relationship between parenting stress and later child progress in young children undergoing intervention programs. It is also well established that there is a strong association between parenting stress and child behavior problems (Baxter, Cummins, & Yiolitis, 2000; Hodapp, Fidler, & Smith, 1998; Lecavalier et al., 2006; Stores, Stores, Fellows, & Buckley, 1998). Recent evidence suggests that high initial levels of parenting stress can lead to subsequent worsening of child behavior problems (Lecavalier et al., 2006). In order to explain such findings, it has been proposed that high levels of parenting stress can have an impact on subsequent parenting behaviors, which, in turn, impact on a child's behavior problems, and outcomes. For example, Osborne, McHugh, Saunders, & Reed (2008b) noted that, in a longitudinal study over a 9–10-month period of time, parenting stress and certain parenting behaviors, namely, limit setting for the child, closely interacted bi-directionally with one another over time, and poor limit setting impacted negatively on child behavior problems.

Contact with professionals concerning diagnosis of ASC often comes prior to engagement with treatment programs. If the contact has been stressful, this may lead to subsequent treatment being less successful, and behavior problems being more pronounced. The limited research to date concerning ASC diagnosis suggests that this process has a high capacity for producing stress in parents of children with ASC (Goin-Kochel et al., 2006; Howlin & Moore, 1997). Mansell and Morris (2004; see also Midence & O'Neil, 1999) found that parents thought that the diagnostic process was slow, chaotic, and badly handled. Parent satisfaction with the diagnostic process has been noted to increase with the fewer professionals that they need to see in order to obtain a diagnosis for their child (Goin-Kochel et al., 2006). Finally, Osborne and Reed (2008) noted that many parents felt that they were given no help and advice following diagnosis. Thus, issues such as the speed of diagnosis, the chain and coherence of referral through the system, and the help offered to parents at the time of diagnosis, may all be implicated in the development of stress in parents during the diagnostic process.

Thus, a picture emerges in which it is acknowledged that the parent plays a pivotal role in the prospects for the child with ASC, and that those parents suffer from high levels of stress, which have, in turn, a negative impact on the prospective outcomes of the child with ASC. Many of these early stressors appear revolve around communication and contact with professionals over the critical period of time in which a diagnosis of ASC is sought and obtained. However, there has been relatively little research effort devoted to discovering the effect of a child's ASC diagnosis on the parents, especially the impact of these experiences on their levels of stress as pressure increases to gain earlier diagnosis.

The current research represents a first attempt to establish some relationships between key aspects of the diagnosis, such as its speed, and parenting stress. Given the practical difficulties in establishing these relationships using a prospective study (which would involve identifying parents of children with ADVC prior to the diagnosis), the current study used a retrospective approach. Obviously, such a retrospective approach cannot provide evidence as solid about such relationships as a prospective longitudinal study, but, given the paucity of findings on this topic, it was thought appropriate to use such an approach initially to establish some tentative findings that may form the basis of subsequent work.

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