

Parents of children with Asperger syndrome or with learning disabilities: Family environment and social support

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Received 28 March 2007; accepted 18 May 2007

Abstract

The study examined the family environment and perceived social support of 33 parents with a child diagnosed with Asperger syndrome and 43 parents with a child with learning disability, which were compared to 45 parents of children without disabilities as a control group. Parents completed the Family Environment Scale and Social Support Scale questionnaires. The comparison revealed significant differences for expressiveness and family system organization and for social support. Parents with an Asperger child perceived their family's expressive feelings as lower and the family organization as higher, and perceived their friendships and other support as lower than the other groups of parent. Parents of the control group reported the highest family support. The study highlighted the need for additional social support for parents with a child with special needs, and accentuated the importance of developing awareness and intervention programs to facilitate parents' coping abilities and their family interactions.

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Keywords: Asperger syndrome; Learning disability; Parents; Family environment; Social support

1. Introduction

A child with special needs has significant effects on family functioning and on family relationships, and may create some changes in the family's routines (Marvin & Pianta, 1996; Turnbull & Turnbull, 1990; Waggoner & Wilgosh, 1990). Parents of a child with special needs

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experience a larger number of care giving challenges such as more health problems, greater feelings of restriction, and higher levels of parental stress or depression, than parents of children without specific disabilities (Quine & Paul, 1985; Roach, Ormond, & Barratt, 1999; Valentine, McDermott, & Anderson, 1998). This study focuses on two main domains. These are the family environment, and social support, as perceived by parents from the three different groups: with a child diagnosed with Asperger syndrome, with a child with learning disabilities and as the control group, families with a child with no specific difficulties.

1.1. Family environment

Various studies have been conducted on parental adjustment and the coping process in families with a child with special needs. Some of them describe the stages and process experienced by parents of children with various disabilities (Blacher, 1984; Falik, 1995; Marvin & Pianta, 1996), indicating that the crisis engendered by the diagnosis that something is wrong with their child is probably the parents' most difficult experience. The difficulties encountered by parents coping with a child with a disability and their familial relationships have been cited as a source of anxiety, overprotection, and rigidity (Lardieri, Blacher, & Swanson, 2000). Numerous studies have examined parents' coping with a child with intellectual disability (ID) (e.g., Blacher, 2001), parents' attitudes and adaptations when coping with children with cerebral palsy (Lin, 2000), or focused on parents' resiliency and expectations within families with a child diagnosed with learning disabilities (LD), ID, autism, with physical disabilities (e.g., Heiman, 2002), or with children with Asperger syndrome (Diggle, McConachie, & Randle, 2002). The literature review shows few studies examining how parents with a child with Asperger syndrome perceive their family relationships and support, compared to studies on families with a child with LD.

1.2. Parents with a child with Asperger syndrome

Asperger syndrome is a neurobiological disorder named for a Viennese physician, Hans Asperger, who first described the disorder in 1944. Asperger syndrome is characterized by significant impairments in social interaction, and restricted and unusual patterns of interest and behavior. These impairments may manifest by difficulties in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction; failure to develop peer relationships appropriate to developmental level; a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people; stereotyped patterns of behavior; repetitive motor mannerisms and activities (APA, 1994). In the 10th revision of the International Classification of Diseases (ICD-10) (WHO, 1992) Asperger syndrome is a subcategory of Pervasive Developmental Disorders. Findings based on clinical work (Ehlers & Gillberg, 1993) show a minimum prevalence of 3.6 per 1000 children (7–16 years of age) and a male to female ratio of 4:1. When suspected and possible Asperger syndrome cases are included, the prevalence rose to 7.1 per 1000 children and the male:female ratio dropped to 2.3:1.

Parents raising a child with Asperger syndrome face a range of difficulties (Diggle et al., 2002). Many of these parents have to provide, in addition to the usual general care, a much more intensive level of care, such as, structuring their child's daily routines, creating opportunities for socializing, daily activities and further education, and providing companionship (Portway & Johnson, 2005).

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