Psychosocial Issues in Childhood Autism Rehabilitation: A Review

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Abstract

This article outlines the research that is available on families coping with a child diagnosed with autism or related disorders. The scant research that is available is highlighted along with the strong call in the literature for further work in this area. Autism has been described as a condition with a greater number of stressors than any other disability. Research that has been completed is explored and used as a basis to examine new directions required to meet the needs of families coping with the demands.Strong recommendations for further research have been developed from the available literature. It is the hope and expectation that such a review and these recommendations, will go some way to assist other researchers interested in furthering the welfare of families coping with autism and related disorders.

Keywords: autism, psycho-social, review, support

Background

The literature on childhood autism clearly indicates that there is limited research available on many aspects of the topic. In particular, there are calls in the literature for research into components of effective educational programs (Schroeder, Le Blanc & Mayo, 1996). Also, there is relatively little research that focuses explicitly on parenting stress and coping in families of children with autism (Hastings, Kovshoff, Brown, Ward, Espinosa & Remington, 2005; Pakenham, Samios & Sofronoff, 2005). Or on the social impact upon families of having a child with an autism spectrum disorder (Higgins, Bailey & Pearce, 2005). Although a few specific treatment methods have been established as efficacious for some children with autism in controlled settings, research examining the translation of these treatments into early intervention programs has been minimal (Stahmer, Collins & Palinkas, 2005). Key writers indicate that there is a need to understand the difficulties faced by those with autistic disorders in educational settings in order to manage and help autistic children handle their learning (Jordan, 2005). In addition, there is a call for researchers to explore the experiences of families engaged in such educational interventions for autism (Hastings & Johnson, 2001).

In short, the literature indicates there is a significant need for research to assist with planning for

health policy and service delivery to address the profound problems faced by families with a child with autism.

What We Do Know

Family impact of autism
The one issue that the research is conclusive about is that families of children with autism report a greater number of stressors (e.g., parental depression and anxiety, difficulties in daily management of the child, financial worries, and concerns over adequate educational and professional resources) than those with children with other disabilities (Hastings & Johnson, 2001; Sivberg, 2002; Tarakeshwar & Pargament, 2001).

A child diagnosed with autism represents a constant source of stress on the family unit, as not only are the caregivers affected, but also siblings and relationships among family members (Higgins et al., 2005). The child with autism typically requires vast amounts of parental time and energy (Tarakeshwar & Pargament, 2001). Mothers of children with autism have been found to experience greater stress and difficulties in adjustment compared with mothers of children with other physical and intellectual difficulties (Pakenham et al., 2005). Research indicates that the brunt of caring falls upon the mother, with fathers helping mainly with supervision rather than physical care or domestic tasks. Siblings also appear not to be involved (Holmes & Carr, 1991). Fathers of children with autism report more financial impact and disruption of family activities (Rodrigue, Morgan & Geffken, 1992).

The child's state is the primary factor behind anxiety and stress among parents with autism (Fleischmann, 2005). Among the most difficult problems that parents mention are, poor language skills; inappropriate and embarrassing public behaviour; disruption and destruction in the home; violence and aggression; inappropriate sexual expression and obsessions with eating and toileting (Gray, 2002). Higher levels of autism symptomatology are associated with higher reported parental stress (Hastings & Johnson, 2001). The more severe the child's symptom, the greater is the degree of parental stress (Dunn, Burbine, Bowers & Tantleff-Dunn, 2001). The extremely antisocial, disruptive behaviours associated with autism, such as self-injurious, tantrum and obsessive/compulsive behaviours, may preclude a normal family life (Higgins et al., 2005). Less favourable outcomes are documented in cases of families with aggressive or violent children (Gray, 2002). The parents in these families have higher levels of stress and have few resources in terms of treatment or residential placement to deal with their situation (Gray, 2002). Mothers appear to be the most severely affected member of the family (Dunn et al., 2001; Moes, Koegel, Schreibman & Loos, 1992).

Surveys among members of families with a family member with autism have found a rise in depression, stress and anxiety (Fleischmann, 2005). Caregivers of a child with autism often experience helplessness; feelings of inadequacy and failure; anger; shock; guilt; frustration; and resentment (Higgins et al., 2005). Longitudinal data suggests that families do not experience a single stressor; rather they experience a pile-up of demands (Pakenham et al., 2005). These studies show that social support is very important in combating depression and stress (Fleischmann, 2005). <>*Lack of available services*

The literature is also conclusive that there is a severe lack of available services for families coping with a member with autism. Services and the provision of short-term breaks (respites) are infrequent and insufficient to meet caregivers' needs (Higgins et al., 2005). The disruptive nature of autistic behaviour, and the lack of public understanding of the disorder, results in limited

availability of child-minding services and respite care, which furthers stresses and demands on caregivers (Higgins et al., 2005).

Coping strategies
Research suggests the effectiveness of coping depends on the positive coping strategies used by the parents, the resources available within the family, and the availability of social support from the spouse, family and informal networks (Tarakeshwar & Pargament, 2001). Fathers of children with autism report more frequent use of wish-fulfilling fantasy, and information seeking as coping strategies (Rodrigue et al., 1992). Acquiring social support and reframing the experience to see some positives are most frequently used coping strategies (Luther, Canham & Cureton, 2005). Hardiness and social support are predictors of successful adaptation (Weiss, 2002). There is no direct relationship between social support and isolation suggesting that some of the parents feel isolated despite receiving social support (Dunn et al., 2001). The Internet allows stressed parents of children with autism to forge ties among themselves and extricate themselves from their isolation (Fleischmann, 2005). <>Poorer adaptation was predicted by other family stresses, unwarranted maternal self-blame for the handicap, and maternal definition of the handicap as a family catastrophe (Bristol, 1987). Research indicates that it is important to discourage parents from using escape and avoidance as a coping style. Encouragement of more appropriate coping methods and receipt of social support is seen as beneficial in buffering the stress and reducing negative outcomes (Dunn et al., 2001).

Research involving parents of autistic children indicates that a positive evaluation of direct services to their child, (e.g., "…believing that my child's program has my family's best interest in mind.") was the most helpful resource in coping with the challenges of autism (Tarakeshwar & Pargament, 2001). Figure 1 provides a summary on stress factors that effect families with an autistic child.
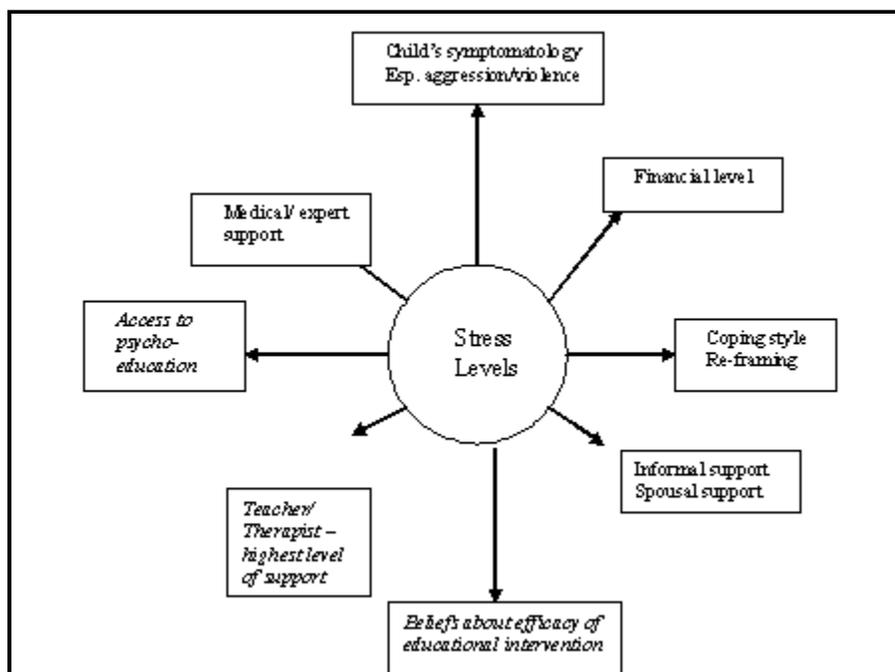
Life stages
As outlined by Figure 2, work by Schroeder et al. (1996) indicates that there are definable stages and critical points of transition for families coping with a child with an autistic disorder. They demonstrate the need to plan transitions in advance. Gray (2002) outlines the likely transition

points. The pre-diagnosis early years are intensely stressful. Diagnosis and placement in treatment and educational programs reduces stress, the child becomes more orderly and the life of the family more settled. Adolescence becomes another period of disruption, with increasing physical and sexual maturity. Increased seizures and parental emotional exhaustion as common problems. Early adulthood also brings increased stresses associated with establishing living and work arrangements.

Figure 2: Stages and critical points of transition for families coping with a child with an autistic disorder.
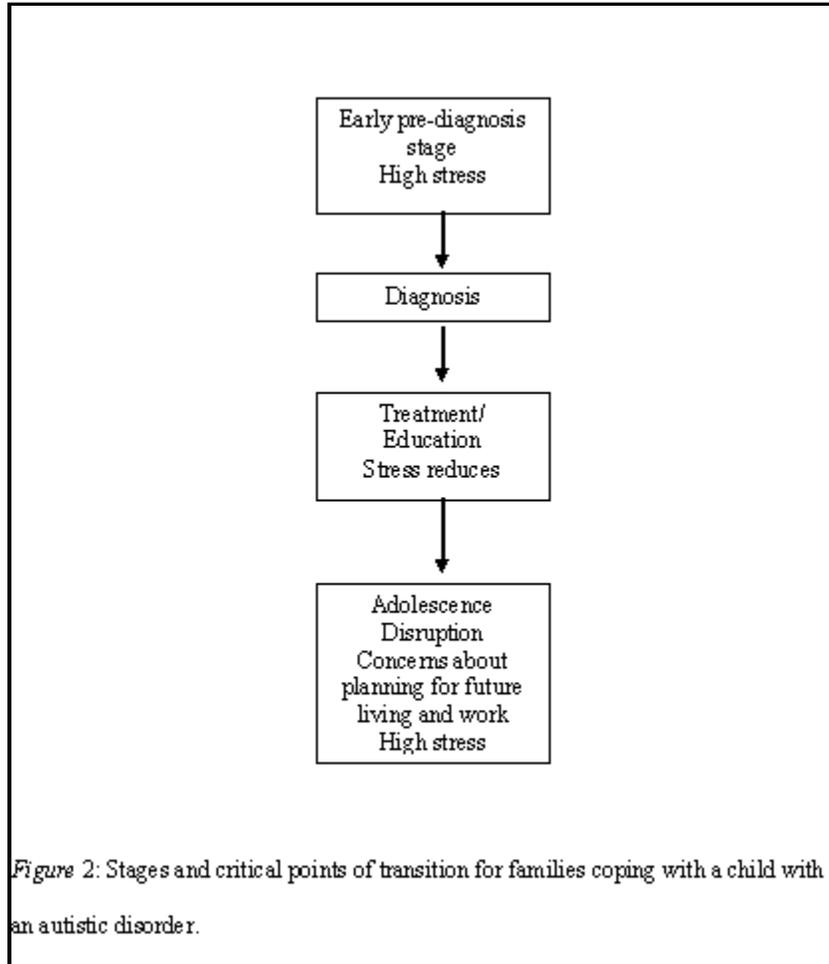
Importance of therapeutic and educational support.

The work that has been completed on educational strategies for autistic children indicates that interventions can have a positive outcome in terms of teaching autistic children new skills and coping strategies (Schroeder et al., 1996). Existing data suggests that stress and depression associated with autism are amenable to psycho-educational intervention (Hastings & Johnson, 2001). Anger management programs based on helping autistic children to recognise triggers, exert control over their physical arousal, and develop strategies through such avenues as role play have been shown through impressionistic reports to be effective (Kellner & Tutin, 1995). Improved verbal and physical sharing has been demonstrated (Sawyer, Luiselli, Riciardi & Gower, 2005). There is some evidence of improvements in the child's sociability, emotional control and attention span during treatment (Gray, 2002). Training courses have been shown to have a beneficial effect on both parent's and children's communication skills (McConachie, Randle, Hammal & Le Couteur, 2005). It is recorded that the best teaching arises from an empathetic understanding and a willingness to be flexible, the worst, from rigidity and an expectation that it is the child who must

change (Jordan, 2005).

Parents are an important part of treatment for a child with autism and have been frequently trained and referred to as *co-therapists* (Pakenham et al., 2005). Importantly, the research indicates that special education teachers received the highest support rating in terms of parental perception of support for coping (Newsome, 2000). <>Several studies have reported decreased parental stress as a result of early intervention with children (Hastings & Johnson, 2001). Indeed, research indicates that beliefs about the efficacy of the educational/therapeutic interventions were associated with lower reported stress (Hastings & Johnson, 2001). As intervention in autism are often intensive, time-consuming, and financially draining, it has been argued there is an ethical imperative to ensure that such programs are assessed through independent research (Hastings & Johnson, 2001). However, the available evidence indicates that few providers have a clear understanding of evidence-based practice, and all providers report concerns about adequate training (Stahmer et al., 2005). Effective evaluation and documentation of efficacy for educational and therapeutic interventions for autistic children through research is seen as essential to ensure a high standard practice (Simpson, 2005).
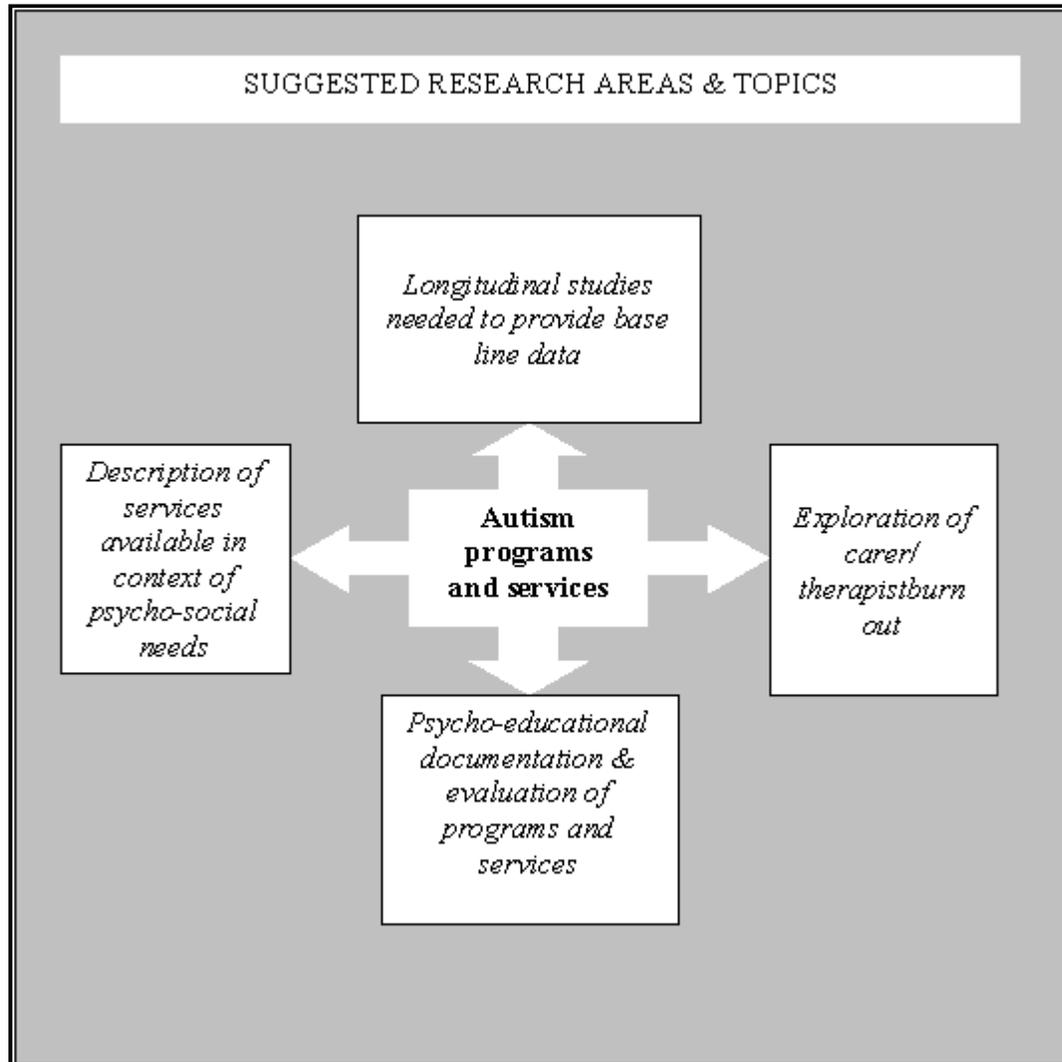
Significantly, stress and burnout contribute to a high turnover of rehabilitation staff (Layne, Hohenshil & Singh, 2004). Research indicates that it is the occupational stress inherent in the job function, rather than individual coping resources or demographics that account for the turnover (Layne et al., 2004). It is believed that turnover can negatively affect an organisations effectiveness, or the degree to which an organisation is able to achieve its goals (Layne et al., 2004).

Moving On - Priority Areas for Research

The available international research points to a number of priority areas of research, if families with a child diagnosed with autism and related disorders are to receive optimum care. In particular, there is presently a call for descriptive and evaluative research on psycho-educational programs and services. It is considered important for the development of this, to date, neglected area to evaluate interventions designed to educate and assist families to cope with autism and related disorders. Such research will first and foremost assist service providers in evaluating their interventions, and thus have quality assurance in the form of reliable and independent information to guide programmatic growth and development. The descriptive research needs to provide insight on the experience from the child and family perspective to ensure developments are mindful of consumer needs. Ultimately the research can make an important contribution to the international community of family, carers, therapists and educators by providing well researched insights and evaluations of a diversity of service and program initiatives for the care of autistic children.

Based on the prior introductory discussion of available research, Figure 3 provides a suggested outline of key parameters required for researchers interested in extending the present work available. It is essential to have longitudinal base-line data that documents both individual and group changes over the period of the child's involvement in the program or service. Such information will provide a basis to build an understanding of the efficacy or otherwise of interventions on the child's development. The base line data needs to be complemented by thorough and independent documentation and evaluation of the particular psycho-educational program under consideration. Particular attention needs to be paid to the issue of therapist/carer burn out. As each program or service will only be one point of connection and support for families with an autistic child, it is also essential to document such service provision in the context of other resources and services available. By taking the four parameters- as outlined in Figure 3 - into consideration a full account of the role, efficacy and benefits of individual services or

programs can be gleaned.

SUGGESTED RESEARCH AREAS & TOPICS

Longitudinal studies needed to provide base line data

Description of services available in context of psycho-social needs

Autism programs and services

Exploration of carer/ therapistburn out

Psycho-educational documentation & evaluation of programs and services

Conclusion

This article outlines the research that is available on families coping with a child diagnosed with autism or related disorders. The scant research that is available is highlighted along with the strong call in the literature for further work in this area. Autism has been described as a condition with a greater number of stressors than any other disability. Research that has been completed is explored and used as a basis to examine the new directions required to meet the needs of families coping with the demands. Strong recommendations for further research have been developed from the available literature. It is the hope and expectation of the author that such a review and these recommendations, will go some way to assist other researchers interested in furthering the welfare of families coping with a child diagnosed with autism and related disorders.

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