

A body of literature discusses the challenges that many parents face if their child is diagnosed with a disability such as autism. Parents of children with disabilities can endure high levels of negative stress, often reported to be in the clinical range as scored on standardized measures. This heightened stress can be due to the unknown prognosis for the child's future and the family's challenged expectations. It can also be related to obtaining high-quality specialized resources that the children often need. Children with ASDs require special education resources, as well as ongoing and intensive intervention and support. In regard to obtaining effective and appropriate support, researchers have identified common barriers that family members face (Ruef, Turnbull, Turnbull, & Poston, 1999; Turnbull & Ruef, 1996). Through focus group meetings, these authors obtained feedback from individuals with disabilities, their family members, and others who support them. They found that a lack of effective resources was a widespread barrier to effectively supporting families. This lack of resources was associated with a limited amount of services, lack of sufficiently trained staff members, high staff turnover, negative staff attitudes, and use of negative practices. Again, realizing the discrepancy between the specialized services available to families of children with autism as compared with the growing number of identified children, it is clear why families may struggle to find support for their children and themselves. In order to obtain these necessary services for their children, parents may be faced with excessive financial burdens and stress (Birenbaum & Cohen, 1993; Singer & Powers, 1993a).

In addition to the emotional and financial stress of trying to obtain appropriate services, parents of children with autism often deal with the stress caused from managing their children's challenging behaviors. In children who have a diagnosis of autism, social communication is delayed and stereotypic behaviors are common. Many of these children rely on using early forms of communication, specifically disruptive behaviors, to get their needs met. They also engage in repetitive and stereotypic behaviors that also present challenges to parents who find it strenuous to successfully interact with their children in more prosocial ways. Research has shown elevated levels of stress for parents of children with autism due to the children's scattered skills and engagement in repetitive and antisocial behavior (Moes, 1995; Plienis, Robbins, & Dunlap, 1988). Parents of children with autism reported greater stress related to caregiving responsibilities, cognitive impairment, disruption in daily activities, and long-term care for their children as compared with parents whose children did not have disabilities. Specifically, findings suggest that parenting a child with a disability increases stress in the areas of everyday management of disruptive behaviors, heavy caregiving responsibilities, and concerns about the child's future when the parents are no longer able to care for the child (R.L. Koegel, Koegel, & Schreibman, 1991). Heavy caregiving responsibilities and problem behaviors can affect the family's daily living situation by limiting engagement in leisure or recreational activities. For example, if a child has tantrums in public areas (e.g., a restaurant, the grocery store), the family may avoid taking their child into the community.

For these reasons, families can develop feelings of social isolation and choose not to engage in such activities. For a family that enjoys spending time in community settings, having a child who engages in disruptive and stereotypic behaviors can be embarrassing, stressful, and overwhelming. This lifestyle alteration can serve as a source of stress for families. In turn, these areas of family stress can inevitably lead to a lowered quality of life for the children and for their family members. The increased stress for parents of children with autism was found to be consistent across family characteristics including geographic location, child's age, and severity of impairment (R.L. Koegel, Koegel, & Surratt, 1992).

In an effort to enhance program outcomes and to support families, many intervention programs for children with autism include a parent education component. Given that children with autism typically spend time engaged in self-stimulatory or other socially avoidant behaviors, they miss many natural opportunities to learn from their environment. Therefore, it has been suggested that they receive intensive intervention throughout the day and during their waking hours (L.K. Koegel, Koegel, Kellebrew, & Mullen, 1996; Lovaas, 1987). There is a large body of literature supporting the inclusion of parents as active team members for their children with autism, and the results of many studies have shown the benefits of this model. Unlike professionals, teachers, and service providers, parents typically spend more time with their children throughout the days and evenings or on weekends. Therefore, they can provide "round-the-clock" intervention for their children (R.L. Koegel, Koegel, Frea, & Smith, 1995). Educators and other service providers most likely provide support to children based on a set weekday schedule, during specific and regular periods of time, and in a particular setting such as a clinic room, classroom, or even in a room

at the child's home. Conversely, parents are natural teachers for their children throughout the week and on the weekend. They are often with their children in numerous settings such as homes, stores, restaurants, airports, parks, beaches, museums, and movie theatres. In addition to the various settings in which parents are frequently with their children, parents also provide teaching opportunities across various daily routines such as mealtime, car rides, bath time, running errands, shopping, and bedtime. Therefore, a benefit of parent education is the likelihood that children's skills will more likely generalize because teaching occurs in many settings.

Although there has been a great deal of work demonstrating the positive effects of including parents into their children's rehabilitation process, the roles of the parents have been only slightly diversified. The majority of literature in this area involves including parents as therapists in their children's intervention program. This model increases the amount of support through a cost-effective model of service delivery, and it contributes to the children's rate of progress (Cordisco, Strain, & Depew, 1988; Cunningham, 1985; R.L. Koegel, Schreibman, Britten, Burke, & O'Neill, 1982; Lovaas, Koegel, Simmons, & Long, 1973; McClannahan, Krantz, & McGee, 1982; Sanders & Glynn, 1981). Parents have effectively learned strategies to reduce problem behaviors (R.L. Koegel, Koegel, & Surratt, 1992; Lutzker, Huynen, & Bigelow, 1998; Lutzker & Steed, 1998; Lutzker, Steed, & Hunyen, 1998; Sanders & Dadds, 1982; Sanders & Glynn, 1981), to improve their children's nonverbal (Anderson & Romanczyk, 1999; Krantz, MacDuff, & McClannahan, 1993) and verbal (Charlop & Trasowech, 1991; L.K. Koegel, Koegel, Harrower, & Carter, 1999; R.L. Koegel, Symon, & Koegel, 2002; Laski, Charlop, & Schreibman, 1988; McGee, Jacobs, & Regnier, 1993; McGee, Morrier, & Daly, 1999) communication skills, and to increase appropriate play skills (Stahmer, 1995; Stahmer & Schreibman, 1992).

Researchers have studied the positive outcomes from including parents as therapists in their children's intervention process to increasing the quantity and availability of intervention for the child (Iacono, Chan, & Waring, 1998; R.L. Koegel et al. 1991; R.L. Koegel, Bimbela, & Schreibman, 1996; McClannahan et al. 1982; McGee et al., 1993) and also to support the family (Clarke, Dunlap, & Vaughn, 1999; R.L. Koegel et al., 2002; Moes, 1995; Santelli, Turnbull, Lerner, & Marquis, 1993; Singer & Powers, 1993a). Research has shown parents of children with autism as effective implementers of behavioral, social, and communication programs for their children (R.L. Koegel et al., 1996; R.L. Koegel et al., 1991, Laski et al., 1988; McClannahan et al., 1982; Sanders & Glynn, 1981; Stiebel, 1999; Vaughn, Clarke, & Dunlap, 1997).

In a study by R.L. Koegel et al. (1982), the authors compared a clinical model of direct treatment for children with autism with a parent education model. The results showed that all of the children improved their levels of appropriate behaviors after participation in the program. However, 3 months after the termination of the program, the group of children whose mothers received parent education continued to improve their skills, whereas the children who received services from a clinician only decreased in appropriate behaviors. In addition, large differences were found between the groups of parents in the amount of leisure time that families reportedly engaged in following intervention. The mothers who received parent education reported dramatic increases in the amount of time that the family spent engaged in

leisure activities, whereas the mothers in the clinician group only reported no difference after the program. These findings support the benefits of parent education over a traditional clinician model of intervention. Including parents in the intervention process resulted in maintained gains in the children's behavior during interactions with their mothers and contributed to the generalized benefits of family functioning. An additional finding reported in this study was that the children's skills did not generalize during their interactions with others (e.g., strangers). Rather, for both groups of children, the treatment provider (i.e., mother or clinician) needed to be present in order for improvements to be maintained. Nonetheless, the study's overall results highlight the limitations of traditional behavioral intervention programs—that is, those that do not include parent education.

Similar conclusions have been proposed by others who assessed generalization of treatment gains to new settings following parent education programs. For parents of children with disruptive behaviors, implementing a self-management program for the parents following parent education was necessary for maintenance and generalization of treatment gains (Sanders & Glynn, 1981). Another study conducted with parents of children with autism (Cordisco et al., 1988) concluded that training may need to occur in multiple settings in order for parents to generalize the use of techniques into new settings.

The Individuals with Disabilities Education Act (IDEA) of 1990 (PL 101-476), its 1997 amendments (PL 105-17), and its 2004 reauthorization (PL 108-446) have included parents in their children's education (Taylor, 2001; Wood, 1995). Parents have particularly been empowered through individualized education program (IEP), individualized family service plan (IFSP), and individual transition plan (ITP) meetings, whereby they can be active participants in the assessment, development, and evaluation of their children's school programs (Fine & Gardner, 1994; Wood, 1995). These positive changes have increased the amount of coordination among children, their families, agencies, and schools. This collaboration between families and service providers also supports the powerful role of parents in their children's education and enhances intervention plans for the children (Fine & Gardner, 1994; Mullen & Frea, 1995).

Parent education can be beneficial not only for children but also for their parents and family members (Baker, Lander, & Kashima, 1991; R.L. Koegel et al., 1996). Several parent education programs have included teaching parents to advocate for their children (McGee et al., 1993) and to provide information and support to other parents and caregivers (Ainbinder et al., 1988; Santelli et al., 1993; Symon, in press; Turnbull, Blue-Banning, Turbiville, & Park, 1999). For example, parents of children with autism can learn techniques for working with their children to overcome socially avoidant behaviors. This positive behavioral change has potentially high reinforcement for parents (McClannahan et al., 1982).

One purpose in designing interventions for parents of children with autism is to reduce the amount of stress that the parents experience resulting from their child's special needs. Various researchers have investigated the effects of social support interventions on families (Ainbinder et al., 1998; Albanese, San-Miguel, & Koegel, 1995; Dunst & Trivette, 1990; Koegel, Schreibman, et al., 1992; Minnes, 1988; Pierce, Sarason, & Sarason, 1996; Plienis et al., 1988; Singer et al., 1999). Social support has

been viewed as a multidimensional model whereby different types of stress can be optimally alleviated with certain types of support (Cutrona & Russell, 1990; Dunst, Trivette, Gordon, & Pletcher, 1989). In other words, to best meet the needs of an individual in distress, the support provided should match the type of stress that he or she experiences.

One theoretical model of loneliness, proposed by Weiss (1974), suggests that different interpersonal relationships can meet different “social provisions” and deficiencies in any area can cause specific types of distress. In his theory, Weiss defined six “provisions” of social support (Russell, Cutrona, Rose, & Yurko, 1984):

1. *Attachment*—providing safety and security
2. *Social integration*—a social network of activities and interests
3. *Reassurance of worth*—providing acknowledgement and praise for skills or accomplishments
4. *Reliable alliance*—available under all circumstances
5. *Guidance*—providing advice
6. *Opportunity for nurturance*—feeling responsible for another person

According to this typology, each provision is typically offered through a specified relationship, although these connections are not rigid. Attachment is most typically provided by a spouse or significant other through a close, intimate relationship. Social integration, along with shared values and concerns, are commonly provided through relationships with friends. Reassurance of worth is notably provided by co-workers or colleagues and may enhance self-esteem or lead to personal empowerment. Reliable alliances, which are usually formed with close family members, provide assistance and can be used during emotional distress. Mentors or other teachers traditionally provide guidance, and children usually provide the opportunity for nurturance.

These provisions have been directly applied to the stresses particular to parenting. Everyday stressors of parenthood are complex and vast and therefore affect each family member in a variety of ways. Parent support systems offer coping strategies to confront the daily hassles that parents may experience. Social support from a variety of sources can also reduce the stress that parents experience. However, the strength of the support has been shown to depend on the individual need (Albanese et al., 1995; Singer, Irvine, & Irvin, 1989), and a body of literature documents the positive effects of providing social support that matches the individual families’ needs (Dunst et al., 1989). Examples of positive outcomes include enhanced quality of life, positive perceptions of the child, fewer time demands by the child with a disability, and improved interactions (Dunst et al., 1989).

In applying Weiss’s (1974) provisions of social support to parenting a child with autism, one can understand the importance of matching an individual’s needs to the types of support offered. Professionals have assisted individuals in obtaining support for themselves through providing opportunities for involvement in support groups and developing skills to build support networks (Singer & Powers, 1993a). The types

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of support, however, vary by individual. Dunst and Trivette (1990) distinguished between formal and informal systems of support. Examples of informal support systems include family members, friends, and social groups (Albanese et al., 1995). Examples of formal support systems include receiving services from professionals and service agencies. Formal and informal social support can be delivered through a variety of models. One-to-one interactions (e.g., counseling, talking to a friend), support groups (e.g., attending professionally mediated focus groups, attending unstructured meetings), professional support services (e.g., receiving parent education), family gatherings, or friendship networks are just a few examples.

The role of the reliable ally has been discussed as an important provision of support for parents of children with disabilities (Singer & Powers, 1993a). This relationship usually develops through a history of repeated contact with an individual who is viewed as trustworthy, and it often consists of common or shared experiences. Self-help support groups and parent-to-parent groups are examples of service systems whereby the individuals are grouped or matched with others who share similar experiences and attitudes surrounding their experiences. Through these interactions, participants receive direct support and, at the same time, work together to increase advocacy.

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