

Coping with autism-support for families

by Christine Dugan Based on the U.S. Department of Education's 2002 report to Congress on IDEA the number of students with autism in U.S. schools has increased by 1354% in an eight-year period from 1991-1992 to 2000-2001 (as cited by the Autism Society of America, 2003). This increase is almost fifty times higher than all disabilities (excluding autism), which has increased in the U.S. by 28.4%. From 1991-1992 to 2000-2001 school years, the number of students with autism that are being served under IDEA has increased from 5,415 to 78,749 respectively (as cited by Autism Society of America, 2003). According to the Center for Disease Control in 2001, autism affects an estimated 2 to 6 per 1,000 individuals and it is the most common of Pervasive Developmental Disorders (as cited by the Autism Society of America, n.d.). Based on these statistics, it is estimated that 1.5 million Americans are believed to have some form of autism (Autism Society of America, n.d.). Autism has been found to affect all races, cultures, socioeconomic statuses, and educational backgrounds (Autism Society of America, n.d.). This rate of growth in autism not only signifies a need for more professionals to be trained to teach individuals with autism, but the need for increased training and support for families of children with autism. Parents of children with autism are coping with a considerable amount of stress and an overwhelming amount of information about the disability. Families of children with autism can benefit from support from professionals, other family members, and society, in order to manage the stress effectively. Parents of children with autism take on many roles in their child's education. They must first recognize and pursue a diagnosis for their child. Once an accurate diagnosis is made, they must find a suitable program and services for their child. Parents need to also act as teachers in the home so that their children learn to generalize skills in the home that they are taught at school. In order for parents to be effective teachers, they need to have specialized knowledge, skills, and information about the efficacy of different treatment programs (Educating Children with Autism, 2001). Because parents are also advocates for their child, they need to have knowledge of special education law and the available services. Due to the stress level of raising a child with autism, parents need coping skills (National Academy Press, 2001). According to a study by Gallagher, (as cited by National Academy Press, 2001), the multiple roles of the parent as teacher, advocate, loving parent, and family member can be extremely demanding for parents. In 2000 Nissenbaum, Tollefson, and Reese (as cited by The National Autistic Society, n.d.), studied the impact of an autism diagnosis on families. They found that parents actually felt relieved at having an explanation for their child's unusual behaviors (National Autistic Society, n.d.). The diagnosis alleviated concerns that they were doing something wrong (National Autistic Society, 2000). As with other parents of children with disabilities, many parents or children with autism go through a grieving process after receiving the diagnosis of autism. Based on research, the education of children with autism is a source of a great deal of stress for many families. Research conducted by Holroyd and McArthur in 1976 and by Donovan in 1988 (as cited by the Autism Society of America, n.d.) found that parents of children with autism experience greater stress than parents of children with mental retardation and Down Syndrome. This stress may be a result of the maladaptive and antisocial behaviors a child with autism may exhibit (Autism Society of America, n.d.). Because individuals with autism often have difficulty expressing even basic wants or needs, parents may feel frustrated when they are unable to determine the child's needs (Autism Society of America, n.d.). The child with autism may exhibit frustration through self-injurious behaviors, aggression, or tantrums that threaten the safety of others (Autism Society of America, n.d.). Parents may feel that the stereotypic or self-stimulatory behaviors (ie: hand-flapping, tapping, lining things up, perseveration on an object), of their child with autism are strange and interfering with functioning (Autism Society of America, n.d.). Because children with autism usually have severe deficits in social skills, such as playing appropriately with peers, parents may find themselves stressed with finding appropriate leisure activities for the child at home (Autism Society of America, n.d.). Some children with autism have difficulties sleeping and may only eat limited food items, which causes another source of struggle for parents (Autism Society of America, n.d.). Family dinners may be disrupted or shortened and bedtimes may be interrupted. Sleep deprivation is common in both the child with autism and the parents of the child. Society reactions can also have a major impact on family stress and may cause the family to avoid community outings or family events (Autism Society of America, n.d.). Families may not go to family get-togethers because the child has difficulty interacting with others (Autism Society of America, n.d.). Families are sometimes embarrassed around extended family members and may have difficulty relating to other family members. Another stress for parents is learning about all of the methods and strategies to teach children with autism. They must learn about these methods so that they can help to determine an appropriate educational placement for their child with autism and so that they can be active members in the IEP process. There are currently many treatment approaches and strategies to teach children with autism. Current methods include Applied Behavior Analysis, Discrete Trial instruction, Picture Exchange Communication System, TEACCH, Floortime, RDI, Social Stories, and Sensory Integration. Once strategies are determined, using some of these methods has potential to reduce family stress and enhance the family's quality of life. Because many children with autism have difficulty generalizing skills, it is extremely important for parents to carry over the child's skill training from school to the home. Parents can also be effective teachers. Families that are taught effective behavioral intervention strategies to manage challenging behaviors, are taught and involved in the functional assessment process, are trained in facilitating functional communication (both verbal and non-verbal), have been found to have greater success at home with the child with autism (Moes & Frea, 2002). When determining behavior plans, professionals need to take into consideration family routines when analyzing challenging behaviors (Moes & Frea, 2002). Behavioral interventions are more successful and meaningful to families when their beliefs, values and goals are taken into consideration (Moes & Free, 2002). A family centered educational approach may be the most beneficial to a child with autism and their families (National Academy Press, 2001). Formal support may come from teachers, IEP team members, doctors, the local education agency representative, and other professionals that treat the child. Informal support may come

through parent networking, parent support groups, families, and neighbors. According to Bristol in 1987, "parents found a positive relationship between adequacy of social support, the use of active coping behaviors, and family adaptation for parents of children enrolled in the TEACCH program" (National Academy Press, 2001, p.34). Coping with a child with autism is difficult and stressful for many families. As with the impact of socioeconomic status and ethnicity of the parents, there is not yet a lot of research on the stress levels of parents based on the child's cognitive level and communication level. Based on current research, in order to cope with the stress of having a child with autism and to experience gains in their education at school and at home, parents need to learn specialized skills and teaching methods that can be implemented at home. Successful collaboration and training with professionals working with the child with autism has the capability of reducing family stress and an increase in the child with autism's communication, socialization, cognitive, adaptive skills and a reduction in maladaptive behaviors in the home environment. Professionals working with students with autism must include the parents as advocates in the IEP process, functional behavior assessments, and behavior intervention plans. Professionals must provide opportunities for parents to be trained in teaching methodologies used at the school. Professionals must also consider themselves a source of support for families of children with autism and be knowledgeable about special education law, treatment methods and scientific research. As a teacher of young children with autism, I have witnessed first hand the benefits of conducting parent trainings and support groups, whether they are on a group basis or an individual basis. Based on parent feedback, parent trainings and support groups are extremely beneficial to those that attend, and most parents express that there is never enough time to talk with the teachers and other parents--there is always a desire to learn more and for more opportunities to collaborate.

About the Author

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