



AUTISM SPECTRUM DISORDER SERIES

Introduction to Autism Spectrum Disorders (ASD)

IDEA Definition of “Autism”

Under our nation’s federal special education law, the Individuals with Disabilities Education Act 2004 (IDEA 2004), all types of autism are classified under one term, “Autism”.

Under IDEA, autism is defined as:

“a developmental disability significantly affecting verbal and nonverbal communication and social interaction, usually evident before age 3 that adversely affects a child’s educational performance. Other characteristics often associated with ASD are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. The term does not apply if a child’s educational performance is adversely affected because the child has an emotional disturbance” [34 C.F.R. 300.8(c)(1)]

IMPORTANT POINT: Most practitioners and educators believe autism is a “spectrum” disorder, a group of disorders with similar features, which can range from mild to severe. Throughout this series we will refer to “autism” as “Autism Spectrum Disorder” (ASD).

Overview of ASD

Originally described in 1943 by Leo Kanner (Colarusso & O’Rourke, 2004), ASD is an increasingly popular term that refers to a broad definition of ASD including the classical form of the disorder as well as closely related disabilities that share many of the core characteristics.

ASD has many variations in symptoms or behavior characteristics. Furthermore, people with ASD vary widely in abilities, intelligence, and behaviors across those indicators. That is, some or all of the characteristics associated with ASD may be observed in a range of mild to very severe forms. For example, some children do not speak; others have limited language. Those with more advanced language skills tend to use a small range of topics, as well as have difficulty with abstract concepts and pragmatic language skills. Repetitive play skills, a limited range of interests, and impaired social skills are generally evident as well. Unusual responses to sensory information such as loud noises, lights, and certain textures or food or fabrics are also common.

Individuals with ASD can exhibit severe mental retardation or be extremely gifted in their intellectual and academic accomplishments (Vaughn, Bos, & Schumm, 2003). While many individuals prefer isolation and tend to withdraw from social contact, others show high levels of affection and enjoyment in social situations. Some people with ASD appear lethargic and slow to

respond, with more focus on objects instead of other people (Scott, Clark, & Brady, 2000). Others are very active and seem to interact constantly with preferred aspects of their environment.

Causes of ASD

ASD is a neurological disability that is presumed to be present from birth and is always apparent before the age of three. Most researchers agree that the collection of symptoms constituting ASD arises from a set of inherited factors (Roider, 2000). Although ASD affects the functioning of the brain, the specific cause of ASD is unknown. In fact, it is widely assumed that there are most likely multiple causes, each of which may be manifested in different forms, or subtypes, of ASD.

In the majority of cases, no specific underlying cause can be identified. However, a variety of factors are being investigated. These include infectious, metabolic, genetic, and environmental factors. Professionals generally agree that symptoms of ASD are triggered by malfunctions in the brain (Szatmari et al., 1998) and that trauma related to abuse or neglect by caregivers is not the cause (Gillberg & Coleman, 2000).

The search for physiological causes of ASD began in the 1960s (Scott, Clark, & Brady, 2000). A working group convened by the National Institute of Health (NIH) in 1995 reached a consensus that ASD probably results from a genetic susceptibility that involves multiple genes. However, the research on chromosomal abnormalities in ASD shows no agreement as to what chromosome or chromosomes are implicated as a cause of ASD (International Molecular Genetic Study of ASD Consortium, 1998; Konstantareas & Homatidis, 1999).

Some parents and families of children with ASD believe that the Measles/Mumps/ Rubella (MMR) vaccine caused their children's ASD. These parents report that their children were "normal" until they received the MMR vaccine. Then, after getting the vaccine, their children started showing symptoms of ASD. Because the symptoms of ASD begin to occur around the same time as the child's MMR vaccination, parents and families see the vaccine as the cause of the ASD. However, just because the events happen around the same time does not mean that one caused the other. Although children receive many other vaccines in addition to the MMR vaccine, these other vaccines have not been identified as possible causes of ASD.

These parents' beliefs and observations were reinforced by a small study of bowel disease and ASD, published by Wakefield and his colleagues in 1998 (Wakefield et al 1998). The study's authors suggested that there was a link between the MMR vaccine and ASD. This study did not include scientific testing to find out if there was a link. The authors relied on the reports of parents and families of the 12 children with ASD involved in the study to make their suggestion. The study did not provide scientific proof that there was any link.

Since this study was published in 1998, a number of other studies have also been published that suggested a link between the MMR vaccine and ASD (Singh et al 1998; Horvath et al 1999; O'Leary et al 2000; Wakefield et al 2000; Kawashima et al 2000), but none of these provide scientific proof of such a link.

To date there is no conclusive evidence that any vaccine increases the risk of developing ASD or any other behavior disorder. Currently, no study provides definitive evidence of an association between ASD and vaccines (Dales, Hammer, & Smith, 2001; Stratton, Gable, Shetty, &

McCormick, 2001). However, continued research is needed to examine the mechanisms of ASD and any possible relationship to vaccines.

Prevalence and Incidence of ASD

According to the 26th Annual Report (U.S. Department of Education, 2004), there were 140,473 students between the ages of 6 to 21 years of age were identified as having ASD. This represents approximately 2.3 percent of all students having a classification in special education, and approximately 0.12% of all school-age students.

A controversial finding is that prevalence figures for ASD have increased dramatically over the past 30 to 40 years, leading some to claim that there is an “ASD epidemic.” In 2007 - the most recent government survey on the rate of ASD - the Centers for Disease Control (CDC) found that the rate is higher than the rates found from studies conducted in the United States during the 1980s and early 1990s (survey based on data from 2000 and 2002). The CDC survey assigned a diagnosis of ASD based on health and school records of 8 year olds in 14 communities throughout the U.S. Debate continues about whether this represents a true increase in the prevalence of ASD. Changes in the criteria used to diagnose ASD, along with increased recognition of the disorder by professionals and the public may all be contributing factors. Nonetheless, the CDC report confirms other recent epidemiologic studies documenting that more children are being diagnosed with ASD than ever before.

Data from an earlier report of the CDC's Atlanta-based program found the rate of ASD was 3.4 per 1,000 for children 3 to 10 years of age. Summarizing this and several other major studies on ASD prevalence, CDC estimates that 2–6 per 1,000 (from 1 in 500 to 1 in 150) children have ASD. The risk is 3-4 times higher in males than females. Compared to the prevalence of other childhood conditions, this rate is lower than the rate of mental retardation (9.7 per 1,000 children), but higher than the rates for cerebral palsy (2.8 per 1,000 children), hearing loss (1.1 per 1,000 children), and vision impairment (0.9 per 1,000 children). The CDC notes that these studies do not provide a national estimate.

Age of Onset of ASD

Symptoms of ASD usually appear during the first three years of childhood and continue throughout life (Friend, 2005). Interestingly, in close to 50% of children diagnosed with ASD, the defining characteristics do not become evident until the child is a toddler, at which point some of the children begin to regress markedly in communication and social abilities (Davidovitch et al., 2000).

Gender Features of ASD

According to the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders-Text Revision (2000), the prevalence rate of ASD in males is about four times higher than females. Other studies have found ratios as high (Kadesjo et al., 1999) or higher (Scott et al., 2002). Although debate exists on this issue, it is clear that ASD is diagnosed much more often in males rather than females. When females do have ASD, however, they are more likely to have cognitive deficits (National Research Council, 2001, cited in Hallahan & Kauffman, 2006).

Cultural Features of ASD

ASD has been found throughout the world in people of all racial and social backgrounds. It exists at approximately the same level in all racial and ethnic groups, and among individuals at all income levels (U.S. Department of Education, 2004).

Familial Pattern of ASD

Recent studies strongly suggest that some people have a genetic predisposition to ASD. Scientists estimate that, in families with one autistic child, the risk of having a second child with the disorder is approximately five percent, or one in 20, which is greater than the risk for the general population (Yirmiya, Shaked, & Erol, 2001).

Educational Implications of Students with ASD

The question as to whether a student with ASD should be fully included in the general education classroom is a subject of great controversy. There are many studies supporting full inclusion (Kliewer & Bilken, 1996; Stainback & Stainback, 1990), as there are studies indicating the need for a full continuum of services (Klinger, Vuaghn, Schumm, Cohen, & Forgan, 1998; Padeliaadu & Zigmond, 1996). Today, more than half the students (57 percent) with ASD receive services in a self-contained classroom or more restrictive environment; approximately 25 percent are assigned to the general education classroom (U.S. Department of Education, 2004).

Appropriate educational programs and determining a diagnosis early are critical to children with ASD. Students with ASD need educational curriculums and programs that focus on improving numerous types of skills. These include communication, social, academic, behavioral, and daily living skills (National Dissemination Center for Children with Disabilities, 2006).

Appropriate educational programs need to be designed for children with ASD to afford them the greatest possible opportunities for future transition to live and work in the community and secure paid employment in competitive settings (Bock & Myles, 1999; Cowley, 2000; Bowe, 2005).

Evidence Based Practice in Working with Children with ASD and Their Families

The best way to help individuals with ASD involves a team effort with parents playing an integral role as respected partners. “No one individual or group of individuals has unlocked all of the complex variables involved in ASD...a coordinated effort by all involved can greatly enhance the functioning level of the child with ASD and concomitantly reduce the tremendous familial stress associated with having a child with a disability” (Koegel, 1995, p. ix - x). Parents need to be seen as collaborators in their child’s treatment programs beginning at the time of diagnosis. As a child ages, he/she should also be increasingly involved in decision making in all aspects of his/her life. For many individuals, there will need to be an interdisciplinary team that functions as a unit throughout the lifespan of individuals with ASD. “Given the intensity and unique pattern of stressors faced by families of children with ASD, the need for parent-professional collaboration in ASD intervention is paramount.” (Volkmar, et al., 2005, pp. 1059-1060).

The Handbook of ASD and Pervasive Developmental Disorders, (Volkmar, et al., 2005) cites eight research-based general approaches that are “most relevant to working with families of children with ASD” (p. 1061). These are defined as:

- “Provide family members with information from the professional literature in an organized and accessible format.
- Train parents to implement instruction techniques or behavior management strategies.
- Help family members apply principles of learning to education and management.
- Work with family members to increase the positive valence and decrease the negative aspects of parent-child relationships.
- Train family members in cognitive techniques in order to modify emotional and behavioral responses.
- Provide family member with empathy, a listening ear, and basic problem solving either through individual sessions or group work.
- Assist family member in obtaining access to resources, services, and basic necessities.
- Assist family member in advocating for the identified child’s needs across the lifetime” (pp. 1062-1063).

Research Basis for Services to Children with ASD in the Home, School, and Community

Children with ASD are a very heterogeneous group (ranging from toddlers who are non-verbal with significant developmental delays to young adults with above average cognitive abilities, but significant social and relating challenges) living and being educated in diverse circumstances. Therefore, it is unlikely that any one approach will work for all children with ASD in all circumstances. The complexity of ASD affects research efforts and the treatments being researched. There are different bodies of research that address different aspects of service delivery to children with ASD and their families. There are bodies of research that address different age groups; school vs. home and community support; different diagnoses within the ASD spectrum; specific treatment, intervention or educational strategies; and comprehensive program models. Also, different approaches are recommended for children and adolescents with Asperger’s disorder. Recently there has been considerable research regarding effectiveness of early intervention for young children with ASD. These bodies of research answer different questions regarding effectiveness (National Research Council, 2001).

There is much controversy in the field regarding appropriate treatment, support and intervention for ASD. Many people have strongly held opinions regarding what is appropriate and most effective. Because the causes of ASD are unknown, the field has been particularly vulnerable to purported “cures” that do not stand up to scientific scrutiny. Different systems each have their own traditions and guiding philosophies regarding supporting children with disabilities. Some of the interventions may conflict with people’s beliefs and philosophies.

There has been a recent push in both education and the social sciences to utilize evidence-based practices in order to maximize outcomes and cost-effectiveness. The Federal No Child Left Behind Act, promotes the use of scientifically based research to improve accountability and educational outcomes. Professional organizations, such as the American Psychological Association, are developing clinical practice guidelines, which promote the use of evidence-based treatments. Evidence-based practices are those that are supported as being effective by high quality, peer-reviewed research. There is not a uniform standard in the education or social sciences for assessing the quality and quantity of research needed to determine that a given practice is evidence-based. A variety of standards has been proposed by the professional and scientific communities.