

because every child deserves a great future

FEATURING  
EMERGING  
TRENDS  
IN

AUTISM

ASPERGER'S DISORDER

LEARNING DISABILITIES

ATTENTION DEFICIT  
HYPERACTIVITY  
DISORDERS

DEVELOPMENTAL  
DISABILITIES

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FALL - 2002

## AUTISM: IS THERE AN EPIDEMIC?

Edward R. Ritvo, M.D. and Riva G. Ritvo, Ph.D., OT.R.

**INTRODUCTION** There is much discussion in the community about the possibility of an epidemic of autism. Clinics, schools, private clinics and other agencies worldwide are being flooded with requests for diagnostic evaluations and for the provision of services. Are we really in the midst of an epidemic, or are there other explanations for the significant increase in the number of children currently being identified with autism?

The first eleven cases of autism were reported in the scientific literature in 1942 by Professor Leo Kanner in Baltimore. It was considered to be a rare condition, characterized by a unique triad of behaviors including delay in language development, repetitive behaviors and a disinterest in social interaction. At the time,

children with autism were seen as very low functioning developmentally, unable to acquire communication skills, and most of them were placed in institutionalized settings. Using these diagnostic criteria, we, and others, conducted surveys of large populations in the United States and Europe during the 1970's, and estimated that autism occurred in about 2 to 5 cases per 10,000 people.

**POSSIBLE EXPLANATIONS FOR THE INCREASED CASE** By the early 1980's, milder forms of autism were identified that resulted in the broadening of the diagnostic criteria. Under these

new criteria now called Autism Spectrum Disorders, studies, especially in Japan and Europe, found the prevalence to be 15 to 20 cases per 10,000. A survey in California of children born between 1987 and 1994 found the prevalence to be 15 cases per 10,000. As research in this area has progressed, even broader criteria have been established. Recently published reports have found the prevalence as high as 50 cases per 10,000. These figures are being confirmed throughout the United States, Canada, Europe and Japan.

There are several factors regarding the broadening of the diagnostic criteria for autism that may account for the recent increase in prevalence. The first would be that by simply expanding our diagnostic criteria to include children

with milder forms of autism (such as Asperger's Disorder), the prevalence would increase. However, this fact alone does not seem to account for the dramatic increases seen in the diagnosis. A second factor could be that many children who previously would have been labeled as mentally retarded are now being diagnosed with autism. Recent studies have noted that while autism is seeing a swift growth, the diagnosis of mental retardation is actually decreasing. Thus, it may be that many cases of autism went undiagnosed in the early years, and children are being moved from one diagnostic category (MR) to another (autism). continued on page 10



# HelpLetter

A publication of The Help Group

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It is with great pleasure that I introduce the first edition of our *HelpLetter*. This publication has been designed to feature emerging trends in Autism, Asperger's Disorder, Learning Disabilities, Attention Deficit Hyperactivity Disorder and Developmental Disorders. We invited leaders in the field to update us on their insights, perspectives and research. We're deeply gratified by their enthusiastic participation in this endeavor.

The *HelpLetter* will be published on a regular basis to provide timely and informative articles to our ever expanding community of colleagues, parents, friends and organizations who share our commitment to children with special needs.

  
Barbara Firestone, Ph.D.

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# BRAIN MAPPING

Susan Bookheimer, Ph.D.

Brain Mapping is a new field of research that is offering exciting new insights into understanding developmental disorders. Brain Mapping can refer to several technologies - PET scanning, MRI scanning, and even invasive, neurosurgical procedures. For research in children, the most promising new technology is called functional magnetic resonance imaging or fMRI. Typical MRI scans show the structure of the brain, but fMRI actually shows the brain at work. Because it is completely safe and non-invasive, fMRI can be conducted even in young children, as long as they are willing to lie still and perform some simple cognitive tasks. An FMRI scan works by measuring where blood flows in the brain while someone is performing a cognitive task - like reading, solving math problems, speaking, or experiencing emotion. By comparing blood flow patterns across groups of children with different neurodevelopmental disorders, research can begin to understand what is unique about brain function in these children, even when the brain structure looks perfectly normal. With a greater understanding of exactly what goes wrong in the brain, scientists can start to focus treatments on the core brain problems and not just the behaviors that children express.



Susan Bookheimer, Ph.D.

Some developmental disorders that are currently being studied using fMRI are dyslexia and autism. For instance, at the UCLA Brain Mapping Center, researchers are using fMRI to see if different brain abnormalities are responsible for different subtypes of dyslexia. Investigators have examined changes in brain function before and after treatment with a computer-based treatment program for children with auditory processing disorders.

Researchers from Yale University Child Study Center have studied differences in how children with autism respond to seeing human faces, and UCLA researchers have found differences in the emotion centers of the brain in children with autism using fMRI. The National Institute of Child Health and Development is now funding several large centers to perform similar research in combination with studies of genetics and treatment of autism.

We are pleased to have established a collaborative relationship with The Help Group and include students of its various programs in our studies. The next few years should show a huge increase in our understanding of how the brain works in children with many different developmental disorders. For more information, contact the UCLA Brain Mapping Center, Dr. Susan Bookheimer, 310-794-6386.

# Understanding

In 1944, Hans Asperger wrote an article about 200 boys from his clinic, all of whom presented with deficits in social and communication skills, unusual behavioral characteristics, unique intellectual abilities and, often, specialized areas of knowledge. He called this condition "Autistic Psychopathy." Dr. Asperger wrote about this disorder around the same time as Leo Kanner was first describing what is now known as autism. While the diagnosis of "Kanner's" autism has been clearly defined for many years, Asperger's Disorder was virtually ignored until the 1970's. Even today, with the advances made in early diagnosis and understanding of autism spectrum disorders, the actual definition of Asperger's Disorder, that is the specific characteristics which must be present to give the diagnosis, remain unclear.

Some diagnosticians use the term Asperger's Disorder to describe all high-functioning individuals with autism, thus making the two terms synonymous. Others use the term Asperger's Disorder only to define children who have similar social and behavioral deficits as autistic children, but have no delay in their language acquisition. The latter belief is what is currently put forward in the Diagnostic and Statistical Manual (DSM) which outlines the necessary characteristics for all mental health disorders. Researchers and clinicians are still trying to work out whether Asperger's Disorder is a form of high-functioning autism or a separate disorder, with different etiology and potentially, different treatment courses and outcomes. The current question is whether these subtypes of autism are truly unique syndromes, or variations of one disorder.

While it is beyond the scope of this article to attempt to settle this dispute, there does seem to be a distinct clinical picture that best defines Asperger's Disorder. The most typical clinical picture is of a child who acquires language relatively early and may actually be very advanced in language skills, with exceptional vocabulary and a tendency to talk at length about favored topics (fixations or pre-occupations), but usually in a lecturing style. They may have either little interest in same-aged peers or tend to try and boss others in efforts to play together. They rarely show interest in typical play activities. Motor skills are often less well developed and the children are often seen as clumsy. A need for order and routine is

accompanied by other rigid qualities that can often lead to emotional dysregulation in situations in which expectations are not met or the child feels uncomfortable with unexpected changes. They often have sensory dysfunctions, including limited food repertoire, increased sensitivity to sounds, lights and touch and a decreased sensitivity to pain and temperature.

Communication may also be affected by marked pragmatic (social/interactive) speech problems due to their tendency to pay limited attention to the expectations and needs of the listener. Other common characteristics are poor insight into their disabilities (which can affect efforts to treat and assist the child); a tendency toward egocentricity and grandiosity; sensitivity to personal slights, but some lack of empathy for other's feelings; and emergence of emotional problems that include anxiety and mood disorders such as depression. Most individuals with Asperger's Disorder lack what is called "theory of mind" or the ability to think about thinking. They are unable to "mind-read" or understand that others may have different thoughts, feelings and experiences than their own. These children often have difficulty with higher-level thinking and executive functioning (organization, problem solving and hypothesis testing skills). A common feature of Asperger's Disorder is that the children can present as relatively normal, being seen as "little professors" or simply "marching to the beat of a different drummer." This presentation style of normal, but quirky is more likely seen in adult-to-child interactions than it is in peer-to-peer interactions. Here, children with Asperger's Disorder display more significant and obvious characteristics.

Intervention requires a multidisciplinary approach to address the broad range of social, communicative, cognitive, academic, and emotional difficulties. Those people working with the child need to have a complete understanding of the underlying characteristics of the disorder that lead to the functional and behavioral problems that are observed. Such insights can often lead to some very practical interventions easily implemented in schools and homes. The degree to which core problems of the disorder can be remediated is a direct consequence of this complete understanding of the individual child.

## Asperger's

## Disorder

# DYSLEXIA

## UPDATE

Bennett A. Shaywitz, M.D. and Sally E. Shaywitz, M.D.

## SPECIFIC READING DISABILITY

Developmental dyslexia is characterized by an unexpected difficulty in reading in children and adults who otherwise possess the intelligence and motivation considered necessary for accurate and fluent reading. Dyslexia represents one of the most common problems affecting children and adults; in the US the prevalence of dyslexia is estimated to range from 5%-17% of school-age children with as many as 40% reading below grade level. It is the most common and most carefully studied of the learning disabilities, affecting at least 80% of all individuals identified as learning disabled. Dyslexia affects boys and girls comparably. Dyslexia is a persistent, chronic condition that stays with the individual their entire life. It is both familial and heritable; about half of children who have a parent with dyslexia as well as half of the siblings of dyslexics and half of the parents of dyslexics may have the disorder.

Current evidence indicates that the central difficulty is within the language system and more specifically within the component of the language system termed phonology that has to do with getting to the sound structure of speech, i.e. the sounding out of words. Results from large and well-studied populations with reading disabilities confirm that, in young school-age children as well as in adolescents, their primary deficit is in this area. Evidence from brain imaging reveals a neurobiological basis for learning disabilities with a difference in brain activation between good and poor readers. We see a pattern of relative under activation in the back of the brain, coupled with relative over activation in front of the brain that may represent a neural signature for reading difficulties experienced by dyslexic readers.

At all ages, dyslexia is a clinical diagnosis: the clinician seeks to determine through history, observation and psychometric assessment if there are: 1) unexpected difficulties in reading (i.e., difficulties in reading that are unexpected for the person's cognitive capacity as shown by his/her age, intelligence or level of education or professional status) and, 2) associated linguistic problems at the level of phonologic processing. There is no one single test score that is characteristic of dyslexia.



The management of dyslexia demands a life-span perspective; early on, the focus is on remediation of the reading problem with reading intervention programs that have proven to be effective emphasizing phonemic awareness, phonics, fluency training, vocabulary and comprehension. The management of dyslexia especially in college and graduate school is primarily based

on accommodation rather than remediation. For these young adults with dyslexia the provision of extra time is an essential accommodation; it allows them the time to decode each word and to apply their unimpaired higher-order cognitive and linguistic skills to the surrounding context to get at the meaning of words that they cannot entirely or rapidly decode. With such accommodations, many students with dyslexia are now successfully completing academic pursuits in a range of disciplines, including law and medicine. In fact, dyslexics are over represented in the top ranks of people who are unusually insightful, who bring a new perspective and who think out of the box.

# CHILDREN WITH ATTENTION DEFICIT HYPERACTIVITY DISORDER

Tim Wigal, Ph.D.

**ADHD** is the most commonly diagnosed disorder of childhood, affecting about 4 percent of school-aged children. The core symptoms include inattention, overactivity and impulsivity. Children have problems focusing on a task or may become bored after only a few minutes or may fail to complete assignments on time. They may seem to be constantly in motion, be unable to stay seated or squirm in their seats. They also tend to act without thinking (e.g., dash into the street without checking for traffic) or say things without thinking it through.

The National Institute of Mental Health, which has sponsored the MTA (Multimodal Treatment study of Children with ADHD) since its beginning in 1994, is now supporting an extended follow-up for the next 5 years. The goal is to carefully collect information on the children who were 7 to 9 years old when they entered the study and are now teenagers in high school. The MTA offers a unique opportunity to study the long-term effects of different types of early treatment of ADHD.

Study results suggest that two forms of treatment - carefully administered medication alone or in combination with a behavioral program - were significantly more effective in reducing the symptoms of ADHD than either behavioral treatment

alone or routine community care (usually medication; although usually not as carefully managed as in the MTA study program). All of these findings were replicated across six study sites (University of California - Irvine; University of California - Berkeley; Columbia University in New York City; Duke University in Durham, NC; Western Psychiatric Institute in Pittsburgh, PA; Long Island Jewish Medical Center in New Hyde Park, NY) suggesting these results apply to a broad range of children and families affected by ADHD.

So we now know that treatment can have a beneficial effect on the behavior of children with ADHD. With different degrees of success, both medication and behavioral-type treatments will improve the symptoms of ADHD and make children less hyperactive, less impulsive and more attentive in school and at home. But the important question that still needs to be answered is whether or not by successfully controlling hyperactivity and impulsiveness and increasing attention we are also improving long-term functioning. In other words, are we making more successful students and/or more competent teenagers, with healthy relationships and a decreased risk of getting involved in substance abuse or delinquency? The ultimate goal of treatment is to make better adults. The MTA follow-up study will provide answers to these important questions.

# THE CRITICAL ROLE OF EARLY INTERVENTION IN AUTISM

Laurie Stephens, Ph.D.

Autism is part of a spectrum of developmental disabilities in which symptoms generally become apparent in children by 2 to 3 years of age. It is also a condition that has shown a dramatic increase in the number of children

affected over the past ten years, such that the prevalence has recently been quoted as high as 1:200 children. Part of the rise in the incidence of autism has been attributed to better diagnostic protocols and more “awareness” of the disability in the community. As parents and professionals are becoming proficient in recognizing

the early symptoms of autism, children are being diagnosed at younger and younger ages. When treatment is begun immediately, the early identification of autism can have a profound effect on a child’s overall development. There is much research and scientific evidence validating that children with autism have a greater chance for successful outcomes when interventions are started at an early age (before 5 years of age). Thus, the development of appropriate, research-based early intervention programs is a primary focus for professionals, educators and parents throughout the United States.

## WHAT IS EARLY INTERVENTION?

Early interventions for the autistic population are developmentally and educationally based treatment programs available to children between birth and 5 years of age. The goal is to provide intensive therapeutic interventions that will allow the child to develop skills in all areas affecting his/her overall functioning level. With regard to autism the best early intervention programs focus on teaching the child to attend to relevant stimuli

(e.g. those necessary for learning), to imitate others, to use and comprehend language or some form of communication system, to play appropriately with toys and to learn to interact in a socially appropriate manner.



*Therapeutic Preschool classroom at The Help Group*

When these skills are taught at a young age, a reduction in maladaptive behaviors, such as tantruming, aggression, self-stimulation (e.g. hand-flapping) and self-injurious behaviors is seen. In addition, early intervention plays a critical role in reducing the need for life-long intervention services.

## WHAT MAKES AN EFFECTIVE EARLY INTERVENTION PROGRAM?

As with most educational programming, controversy abounds when discussing what is necessary for early intervention with autistic children. This controversy is not so much about the apparent need for such programs, but rather how the services should be delivered and how often. However, every state that has designed educational “best practices” for autism has listed the following characteristics as essential in any early intervention program:

- The teaching techniques should be modeled upon research-based methods and curriculum. Data (record keeping) must be kept to monitor the child’s acquisition and generalization of skills.
- A highly supportive teaching environment, including the use of specially trained teachers, assistants and aides.
- Built in strategies for generalization.
- Due to the nature of how autistic children learn, the teaching program must be highly structured, predictable and routine-oriented.

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# The Help Group because every

# Group

## SPECIALIZED DAY SCHOOLS

The Help Group's specialized day schools offer elementary, middle school and high school programs and are certified by the California State Department of Education. Each of the schools provides diagnostic prescriptive teaching, small classes, individualized curriculum and enrichment activities to maximize learning.

**Summit View School** fosters the fullest potential of students with specific learning disabilities. In this dynamic environment, students build their academic skills, experience the educational process as positive and rewarding and recognize their strengths and abilities.

**Village Glen School** serves children with social and communicative disabilities, including high functioning autism and Asperger's Disorder. It offers a unique, individualized education in a nurturing, therapeutic environment that fosters the development of socialization and communicative skills.

**Young Learners Therapeutic Preschool and Early Intervention Center** is designed for children with neurodevelopmental and social emotional delays. These programs assess the nature and degree of the challenges each child is confronting and fosters early development through an interdisciplinary approach.

**Sunrise School for Autism and Developmental Disabilities** is dedicated to promoting communicative, behavioral, social, academic, motor, adaptive and independent living skills. These comprehensive programs enable each student to maximize his/her potential.

**Pacific Ridge School** addresses the educational needs of students who require an intensive therapeutic day school due to emotional and behavioral disabilities. Psychodynamic and behavioral techniques complement the diagnostic teaching process in helping students to experience success and achievement.



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## CLINICAL PROGRAMS



Serving children, adolescents, young adults and families, **The Help Group Child and Family Center** offers mental health, child abuse prevention and intervention, psychological counseling and speech and language therapy programs in clinic, home and/or school settings.

**The Mental Health Services Programs** provide psychiatry, individual, family and group therapy, case management, day treatment, after school enrichment for at-risk children and vocational services.



**The Child Abuse Prevention and Intervention Programs** include child and family counseling, foster family recruitment and placement, family preservation, teen parenting counseling, parent education and family reunification counseling.



**The Autistic Spectrum Disorders Program** features multidisciplinary assessment, intervention, family support, therapeutic preschool programs, after school programs and summer camp for children with autism, high functioning autism and Asperger's Disorder.

**The Help Group - UCLA Neuropsychology Program and The Help Group - UCLA Center for Autism** are innovative partnerships of The Help Group and UCLA. These programs provide state-of-the-art clinical services and enrich the field of knowledge through their research and educational endeavors.



Dedicated to children, adolescents and young adults with emotional disabilities and individuals with developmental disabilities, **Project Six** creates therapeutic living opportunities in nurturing, home-like settings. With a full continuum of integrated services, these programs promote personal and interpersonal development, vocational and independent living skills.

Third, many more general practitioners, physicians, psychologists, mental health providers, teachers and parents are becoming increasingly aware of the symptoms of autism, are making more accurate diagnoses and seeking the appropriate help needed. Finally, within the last five years there has been a rapid increase in services provided to children within the autistic spectrum, leading parents and clinicians to become more open to such a diagnosis. When all of these factors are taken into consideration, it is clear that the broadening of the diagnostic category of autism has led to at least part of the so-called epidemic.

Another possible explanation is that some new form of environmental factor(s) is/are responsible, either by themselves or in combination with an inherited predisposition. Or, it could be that a certain gene is responsible and they are becoming more harmful as they pass from one generation to the next in some families. Supporting this theory is the fact that there are many more families with multiple children being identified each year.

Other areas of investigation into the increase of autism are ongoing. Currently, many studies are being conducted both here and abroad in an attempt to determine why so many new cases of autism are being identified. Some of the current thoughts have not been substantiated through scientific research. For instance, there is a theory that the MMR vaccine may lead to an increased risk for children developing an autistic condition. However, a recent study in England reports that the same proportion of children has been vaccinated over the past three decades while the number of autistic children has been increasing. Therefore, there is no evidence for a causal link between autism and the MMR vaccine. Investigation in this area is continuing. Similarly, scientific studies of pesticides, radiation hazards, allergens, yeast infections, etc. have also failed to identify causative environmental factors. One study concluded that children conceived via in vitro fertilization have fifty percent higher rates of developmental disabilities. Could this group be a significant contributor to the increase in autism? Could rising maternal age be a factor? Further research in these areas, along with genetic and brain research, is necessary to search for the answer to this puzzling question.

**FURTHER RESEARCH** There is much excitement in the research community regarding new tools being developed to study genes and the human genome, as well as major technological advances in neurosciences that will enable us to pry open the secrets of autism, and lead the way to a cure. In the last three years we have seen an increase in funding for research and services throughout the world, although we still have a long way to go to match the available funding for other disabilities. We now have a large population to study, the tools to study it with, and hopefully the public attention and support we have been desperately seeking for years. It is time to move forward in our endeavors.



**EARLY INTERVENTION IN AUTISM**

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- A functional approach to behavior difficulties must be implemented.
- Parent support and training is mandatory.
- The program should be staffed to provide the necessary support to allow each individual child to progress at his/her own pace.

It has been well documented that autistic children do not learn in traditional preschool or group settings. They require individualized, one-on-one teaching to address the uniqueness of their communication, social, behavioral and learning difficulties. When autistic children are provided with intensive early intervention that is specifically designed to meet the breadth of their needs, the speed of the children's development can be increased and may lead to a better long-term prognosis. Appropriate interventions for autistic children should begin as early as possible to take advantage of the "window of opportunity" that exists while the child's brain is still developing and is malleable. Much research has shown that there are critical periods for developing certain skills (such as the ability to use verbal language proficiently) and that the earlier these skills can be taught, the better chance a child has of fully mastering them.

The Help Group recently opened its Young Learners Therapeutic Preschool and Early Intervention Center for toddler and preschool-aged children with autism. This innovative program utilizes the most effective early intervention practices in the field. While there is not a cure for autism currently, intensive early intervention is key to maximizing the child's growth and development. For further information, please contact Dr. Laurie Stephens at 818-947-5542.

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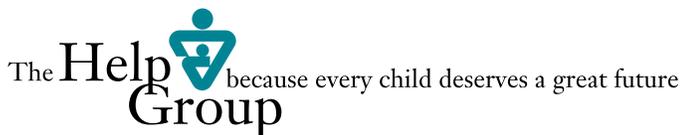
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Since 1975, The Help Group has been dedicated to serving young people with special needs related to autism, Asperger's Disorder, learning disabilities, emotional development, mental retardation, and abuse and neglect. The Help Group's wide range of innovative special education and clinical programs are inspired by its belief that dignity, hope, opportunity, and love are the birthrights of all children.

One of the largest and most comprehensive non-profit organizations of its kind, The Help Group is highly regarded for its high standards of excellence, unique scope and breadth of services, and professional training and research programs. During the past year alone, The Help Group has touched the lives of over 5,000 young people and their families. With over 500 staff members and four major campuses comprising state-of-the-art educational and therapeutic facilities, The Help Group looks forward to opening the doors of opportunity to many more children throughout the years ahead.

At the heart of its efforts is the commitment to helping young people fulfill their potential to lead positive, productive and rewarding lives. Working together, the Board of Directors, staff, governmental colleagues, philanthropic friends, parents, and volunteers have created a very special partnership of caring...*because every child deserves a great future.*

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