Children with AD/HD and Their Families

Contents

What is Attention Deficit Disorder?
Characteristics of AD/HD
Family Considerations
Program Considerations
Summary
References
Resources

What is Attention Deficit Disorder?

Attention Deficit Disorder, or ADD, is the popular name for Attention Deficit/Hyperactivity Disorder (AD/HD), the most commonly diagnosed child psychiatric disorder in the United States. The name ADD was coined in 1980, when the disorder was first recognized.

Today AD/HD accounts for at least half of all referrals to child counseling centers. Estimates of the number of children in the United States diagnosed with AD/HD range from three percent to ten percent. Of children referred to mental health clinics, about three to five percent have AD/HD. Of children identified as having specific learning disabilities, about a third also have AD/HD, while among children identified as having serious emotional disturbances, as many as two-thirds also have AD/HD.

AD/HD is a neurobiological disorder that can have multiple causes. Heredity may play a role, and evidence suggests that neurological, neurochemical, or in some cases, toxic factors may also be involved. Other factors, such as other medical conditions a child may have, side effects from medication, family functioning, and environmental conditions, can aggravate the disorder.

AD/HD is difficult to diagnose because its onset tends to be gradual and its symptoms, which are not necessarily obvious, can phase in and out under different circumstances. Some children give an indication of the disorder before they are born; others are not diagnosed until their teen years. Regardless of how AD/HD is defined or diagnosed, the number of children exhibiting the characteristics of AD/HD has soared since the disorder was first recognized sixteen years ago.

Characteristics of AD/HD

AD/HD involves the basic processes related to orienting, focusing, and maintaining attention, and results in inadequate attention to tasks, both academic and social. The disorder may also include impulsive and excessive nontask activities, like fidgeting. Young children may squirm in their seats or have difficulty staying seated altogether.
Older children may feel restless, which aggravates their inattention.

Children with AD/HD are distracted by the simplest things. They often find it difficult to wait their turn in games or group situations, to follow through on instructions, or to listen to what is being said to them. They have difficulty staying interested in tasks or play activities and shift quickly from one uncompleted activity to another. They have difficulty playing quietly and often talk excessively. These children often engage in physically dangerous activities (like running into the street without looking) without considering possible consequences. Children with AD/HD are often moody and may have frequent, sometimes violent, temper tantrums and low self-esteem.

Because a child with AD/HD has difficulty listening, following directions, organizing thoughts, or completing assignments, there may be a contradiction between the child’s intellectual ability and his or her achievements. Children with AD/HD must struggle to focus and channel their energy. They seem hyper aware and alert, but often they are paying attention to the wrong things or to too many things.

Most children exhibit many of these traits at some time but will not have AD/HD. The disorder is indicated when these traits appear consistently, when the child is unable to change or control them, and when these traits do not stem from other psychological or physiological causes.

**Family Considerations**

Hyperactivity can impose tremendous stress on a family. The family may experience a constant and sometimes overwhelming sense of chaos and anxiety. Intense sibling rivalry is common in families with a hyperactive child. The focus of both the family and the care provider should be on strengthening the self-esteem of parents and children and rebuilding family harmony. It is also important to remember and emphasize that the stress is caused by the symptoms of AD/HD, not by the child.

Many times, parents of a child with AD/HD have negative feelings, which places additional pressures on them. They may blame themselves for their child’s behavior. If information about AD/HD is unavailable to them or inadequate, they may be confused about the issues surrounding the condition, unaware of their options, and overwhelmed by the choices they are expected to make.

In addition, they may be blamed and/or criticized by others for their child’s condition. Teachers, doctors, friends, even strangers may offer advice that is confusing, contradictory, and often insulting. They may imply that the child is misbehaving because the parents are incompetent or because the child is not receiving enough love and/or discipline.

Feelings of failure and helplessness can manifest themselves as anger toward the child, which can then lead to feelings of guilt for the parents. The result is a commotion of feelings: resentment toward the child, guilt over the resentment, a desire to love and defend the child, and more guilt about not being able to help and protect the child.

**Program Considerations**

Programs that serve families who have children with AD/HD need to be flexible and individualized to the families that will be served. Not all families will want or need the same services. Successful programs are versatile and creative in their approach to programming for families.
Parent involvement is important in improving social, psychological, and educational outcomes for all children. For children with AD/HD, such involvement is even more crucial, because parents can provide important information about their children’s strengths, needs, and interests.

Programs that are effective in meeting family needs encourage frequent parent-professional and professional-professional communication through regular telephone conferences, face-to-face meetings, and written exchanges. For example, a child may carry a small notebook in which the parent and the care provider(s) can correspond with each other. It is important to remember that parents can become even more frustrated if they are not notified about their child’s development unless the news is bad or after the child has fallen so far behind that catching up seems impossible.

Because children with AD/HD sometimes require services from a variety of different professionals, such as educators, physicians, and counselors, it is important for respite programs to establish policies and procedures for communicating with personnel at other agencies. Good communication will ensure the most effective collaboration of services.

Care providers also need to recognize that not all parents will be able or willing to become actively involved in the respite program. In addition to the stress of career and family responsibilities, single parenting, and economic difficulties that many families face, the parents of children with AD/HD must also face the demands of parenting children who need a great deal of attention and supervision. Parents often need a break from the constant attention that children with AD/HD demand, and they may welcome the opportunity not to become involved in the child’s respite activities.

Siblings of children with AD/HD may often feel forgotten by parents struggling with the demands of a child with AD/HD and may become jealous and resentful. On the other hand, siblings can also be assets to care providers because they can give some much-needed stability in the life of a child with AD/HD. Some respite workers are comfortable caring for several siblings at a time. Others may not want to or may feel they are not qualified. Still others may feel that it is not the best situation for the child with AD/HD. Again, leave it up to families to negotiate how siblings are to be dealt with. One possible approach is for providers to stagger their involvement by including activities with siblings every other visit or once a month, for example. Remember, a family may not feel less stress if the child with AD/HD is receiving services but other siblings are acting out.

Consistency is key to working with children with AD/HD and their families. It is crucial that a child with AD/HD have an established routine and that the routine not be disturbed when the child is in a different setting. Breaks in routine could lead to a tired, hungry, irritable child, and more likely, frequent tantrums. It is important that the pattern of the child’s day not change from home to school to respite; from parent to teacher to care provider. Since parents know their children best, they should familiarize care providers with their children’s needs, their physical routines (sleeping, waking, eating, etc.) as well as their social routines (school, play, television, etc.). Parents also can instruct providers in the kinds of reinforcement their children respond to best.

Because children with AD/HD need skilled care, care providers need to be well trained. When the family trains the provider, the provider learns the family’s particular needs and is more prepared to meet them. At the same time, having the family train the provider causes the least disruption in the routine of the child with AD/HD and the family as a whole. This is especially important for a child who is on an established schedule. During training, the care provider should also observe the child with AD/HD
in the classroom, in a therapy session, or in other settings to better understand the child’s behavior and how to work with the child.

Just as information from the parent is invaluable to the care provider, the respite program can help parents learn how to establish proper boundaries for their children and how to resist buying into power plays acted out by the children. Respite programs can offer support groups where parents and providers get together in informal settings to discuss the children and their experiences caring for them. This gives parents a chance to become better acquainted with the respite providers and their strengths, and to network with other parents who are coping with similar issues.

Summary

It is important for families and care providers to remember that many characteristics of children with AD/HD are socially desirable and pleasant. They are often spontaneous, enthusiastic, intense, curious, and energetic, qualities that help motivate both themselves and others. Children with AD/HD tend to have rich imaginations and can quickly generate new and unconventional ideas, and they often are intuitive and sensitive. Most importantly, the majority of children with AD/HD grow up to lead successful, well-adjusted lives (Goldstein & Goldstein, 1990).

References


Resources

C.H.A.D.D. (Children and Adults with Attention Deficit Disorders), 409 NW 70th Avenue, Suite 109, Plantation, FL 33317. (305) 587-3700.

About the Author: Marissa Lewis has been the Information Specialist at ARCH National Resource Center since 1994. She holds a B.A. in Linguistics and is pursuing an M.A. in Communication Studies from the University of North Carolina.

Special Thanks to Richard Donner of Program Uplift, Judy Sturdivant of Vermont Federation of Families, and Barbara Huff and Elaine Slaton of Federation of Families for Children’s Mental Health for reviewing this factsheet and providing valuable insights and suggestions for improvement.

ARCH Factsheet 47, February, 1997

This factsheet was produced by the ARCH National Resource Center for Respite and Crisis Care Services funded by the U.S. Department of Health and Human Services, Administration for Children and Families, Administration on Children, Youth and Families, Children’s Bureau—Cooperative Agreement No. 90-CN-0178 under contract with the North Carolina Department of Health and Human Services.