

## **AD/HD Is a Developmental Disability**

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Attention-deficit/hyperactivity disorder (AD/HD) is a developmental disability when it creates a functional impairment that impacts the daily functioning of child, according to the Centers for Disease Control and Prevention (CDC), National Center on Birth Defects and Developmental Disabilities (NCBDDD).<sup>1</sup> The Administration on Developmental Disabilities, part of the U.S. Department of Health and Human Services, is charged with implementation of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act). The DD Act itself does not contain a list of who is to be considered to be a person with a developmental disability, but concern exists among families dealing with AD/HD that eligibility for many programs relies on a rigid interpretation of “developmental disability” and that it is not consistently implemented from state to state, even among state Councils on Developmental Disabilities.<sup>2</sup> Inconsistency of terminology between governmental agencies is a reality as federal programs are implemented within the states.

This document provides guidance to families of children with AD/HD and advocates who work with individuals affected by AD/HD to explain how AD/HD meets the definition of a developmental disability as included in the DD Act, and can assist families and/or adults with AD/HD in advocating for services from programs funded by the DD Act.

As defined in the DD Act, a developmental disability is “a severe, chronic disability of an individual that

- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments;
- (ii) is manifested before the individual attains age 22;
- (iii) is likely to continue indefinitely;
- (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:
  - (I) Self-care.
  - (II) Receptive and expressive language.
  - (III) Learning.
  - (IV) Mobility.
  - (V) Self-direction.
  - (VI) Capacity for independent living.
  - (VII) Economic self-sufficiency; and
- v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.”<sup>3</sup>

AD/HD is a common neurobiological condition affecting 5-8 percent of school-aged children; the symptoms persist into adulthood in as many as 60 percent of cases, i.e., approximately 4 percent of adults.<sup>4</sup> According to the *Diagnostic and Statistical Manual of Mental Disorders*, it is characterized by developmentally inappropriate levels of inattention, impulsivity, and hyperactivity. The DSM-IV-TR criteria requires that AD/HD symptoms causing impairment were present before age 7 years and are present in two or more settings.<sup>5</sup> In addition, clear evidence must exist of interference with developmentally inappropriate social, academic or occupational functioning.<sup>6</sup> Thus, AD/HD meets the definition of a developmental disability as noted in 42 U.S.C. 15002 (8)(i-iii).

Although people with AD/HD can be very successful in life, without identification and proper treatment, AD/HD may have serious consequences, including academic underachievement and school failure, problems in social relations, risk for antisocial behavior patterns, teen pregnancy, and adverse driving consequences.<sup>7</sup> As noted above, AD/HD persists

from childhood to adolescence in the vast majority of cases, although the symptom area of motor activity (hyperactivity) tends to diminish with time. Yet, many adults with AD/HD learn coping strategies and compensate quite well with early identification and treatment.<sup>8</sup>

In determining significance of disability, the regulations implementing the Rehabilitation Act of 1973 define an “individual with a significant disability” as someone who has serious limitations in “one or more functional capacities (such as mobility, communication, self-care, self-direction, interpersonal skills, work tolerance, or work skills)”.<sup>9</sup> Frequently, functional limitations are identified as an activity or behavior that an individual cannot perform or performs with difficulty. For individuals with AD/HD, serious functional limitations may also result from behaviors that the individual can perform, but fails to perform with sufficient frequency, adequate intensity, in the appropriate manner, or under socially expected conditions. Serious functional limitations may result from behaviors that occur too frequently, too intensely, last too long, or occur when and where they should not normally occur. Research demonstrates that AD/HD meets the additional criteria for a developmental disability as required in 42 U.S.C. 15000(8)(iv-v). How each of these areas may be impacted for a person with AD/HD is discussed below.

### **SELF-CARE**

An individual with self-care deficits may not learn experientially, and therefore may show signs of developmental delays and/or deficits in the mastery of self-care competencies such as those related to health, safety, nutrition, and money management. For most individuals, self-care competencies are usually mastered throughout the developmental stages in their lives.

Deficits in attention, reasoning, working memory, academics, communications and coordination caused by AD/HD and co-existing disabilities can affect a person's ability to perform self-care activities at home, in the community, and at work. These deficits may include problems with reasoning, processing and cognition that may cause an individual to repeatedly make poor decisions about basic necessities of life and frequently engage in dangerous activities without considering possible consequences; academic deficits, particularly in rote learning subjects requiring executive functioning skills, that may severely limit an individual in the management of finances and in self-care activities that require following written directions; language deficits that may cause an individual serious difficulties in carrying out basic everyday functions such as shopping and banking that involve communication with others; memory deficits that may lead to forgetting to observe job-related safety precautions or to take prescribed medications at the designated intervals; reduced response times resulting in accident proneness; and attention deficits that heighten distractibility, as well as behavioral deficits such as impulsive and/or explosive behaviors or the apparent disregard for rules and safety procedures that may result in accidents.

### **LEARNING (INCLUDING RECEPTIVE AND EXPRESSIVE LANGUAGE)**

The CDC estimates that as many as 50 percent of children aged 6-11 who have been identified with AD/HD also have learning disabilities, including deficits in receptive and expressive language as well as significant difficulties in learning, especially as it relates to skills requiring executive functioning.<sup>10</sup>

For individuals with AD/HD, 30 percent or more will repeat a grade, up to 46 percent will be suspended from school, between 10-20 percent will be expelled from school, and 10-35 percent fail to graduate from high school.<sup>11</sup>

Receptive communication problems in school and work environments include difficulties with following oral and written instructions, interpreting written materials (particularly job manuals, work orders, diagrams and signs), understanding complex sentences and/or language subtleties, completing job applications, learning new tasks or procedures from written materials or verbal instructions, remembering information (especially multi-step directions), and differentiating important information from unimportant information.

Sixty percent or more of individuals with AD/HD will have poor handwriting and therefore the inability to prepare a written report or letter due to spelling, grammatical, or organizational difficulties.<sup>12</sup> They also demonstrate a lack of organized development and focus in describing a topic; inadequately describe skills, work, and educational experiences on a job application or during employment interviews; and are unable to repeat or relay instructions to coworkers and others.

## **MOBILITY**

Upwards of 47 percent of children with AD/HD meet the diagnostic criteria for having a Developmental Coordination Disorder.<sup>13</sup> Furthermore, children with AD/HD are more likely to experience injuries due to accidents. Mobility may also be impacted by reading problems that interfere with one's ability to read a bus or train schedule, to determine how to transfer, or to read road signs and maps. Calculation and number concept problems may interfere with the ability to pay for public transportation or budget for transportation. Spatial orientation and

perceptual problems influencing directional sense may result in frequently getting lost and an inability to navigate within the environment, be it travelling within the community or finding one's way around the inside of a building or complex. Time-sense deficits may result in chronic lateness or serious problems in planning and/or comprehending public transportation schedules. Directional confusion may also pose significant safety problems because of difficulties in the integration of visual information.

Limitations in organization, sequencing, and planning that result from deficits in attention and higher-level conceptual deficits may preclude an individual's ability to make arrangements for transportation, particularly if these involve modification of simple routines, one or more transfers, or coordination of connections. Problems with comprehension or attention may result in errors, such as taking the wrong bus or getting off at the wrong stop, consistently taking wrong turns while driving, and/or accident proneness.<sup>14</sup> Memory difficulties may interfere with the individual's ability to navigate due to the inability to recall landmarks and directions. And coexisting language deficits or learning disabilities may interfere with the ability to understand spoken directions.

### **SELF-DIRECTION**

Self-direction describes the capacity to organize, structure, and manage activities in a manner that best serves the objectives of the individual. Adequate self-direction requires that an individual be able to plan, initiate and monitor behavior with respect to an identified outcome. Such functions require the mobilization of cognitive and physical resources, including the abilities to organize, structure, and plan appropriate approaches to achieve necessary tasks and to do problem-solving. These executive functions are frequently limited by those with AD/HD.

Individuals with AD/HD and co-existing disabilities are often impaired by lack of insight, i.e., inadequate awareness of their strengths and weaknesses, an inability to monitor their performance to detect if it is meeting the demands of the environment, and inability to adjust their behaviors and activities if the current performance is not adequate. The impact of these difficulties can affect the individual's ability to monitor his or her behavior in school, at home, in the community, at work; to select and plan appropriate educational and vocational objectives and identify suitable strategies to achieve the objectives; and to adequately respond to work or educational demands.

Limitations in self-direction include shifting from one activity to another without purpose, failing to follow through and complete assignments, inability to set up and implement a study schedule or job search, and requiring a higher degree of supervision than typically provided to other workers performing the same tasks. These same limitations in self-direction are often evident in problems related to time management, such as underestimating the time (and energy) needed to complete work assignments, causing other responsibilities to not be addressed, missing or being late for appointments and meetings, and making decisions impulsively without considering previous plans or experiences.

Adequate self-direction requires cognitive flexibility or the ability to adapt and shift quickly, accurately, and appropriately in response to changing work requirements. Individuals with AD/HD who also have serious limitations in gathering, organizing, and analyzing information may experience cognitive disorganization and a lack of focus, often misinterpreted by others as lack of motivation or laziness; or they may experience a cognitive rigidity caused by trying to overcompensate for cognitive deficits. Difficulties in transition to new circumstances

pose problems when there are changes in work requirements or conditions, particularly in settings that may require teamwork.

### **CAPACITY FOR INDEPENDENT LIVING AND ECONOMIC SELF-SUFFICIENCY**

Most of the issues already addressed in this document directly impact a person's ability to fully deal with independent living and economic self-sufficiency. A study conducted in 2000 found the total excess cost of AD/HD in the U.S. was \$31.6 billion. Of that amount, \$1.6 billion went towards treating patients with AD/HD; \$12.1 billion was spent on all other healthcare costs of individuals with AD/HD; and the value of work lost from people with AD/HD and their adult family members was \$3.7 billion.<sup>15</sup>

A 2005 study on co-occurring conditions and costs related to adults with AD/HD found that "adults diagnosed with ADHD had significantly higher outpatient costs... inpatient costs... and total medical costs... compared with the non-AD/HD cohort."<sup>16</sup> For adults with AD/HD, additional issues that greatly impact the ability to sustain capacity for independent living and economic self-sufficiency include deficits in interpersonal skills, work tolerance and work skills. Interpersonal skills are required for an individual to work with supervisors and others to facilitate the normal or accepted flow of work activities. Interpersonal skill limitations may be the direct and immediate result of the individual's AD/HD symptoms.

Communication deficits create serious problems for the individual in interpreting and responding appropriately to the behavior and communications of others. These individuals may not be able to correctly interpret subtle, nonverbal cues that provide feedback on school or work performance, such as body language, facial expressions, or tone of voice. Such deficits may

result in inappropriate discipline at school or job loss if someone does not understand the improvements needed in their work performance.

Inability to correctly read the social context creates the potential for disruption of normal work relationships and problems on the job or in the classroom. Interpersonal skill limitations may be caused by AD/HD deficits related to social competency and emotional maturity. These deficits may manifest themselves as inappropriate behaviors and language, lack of inhibitions, impulsivity, sudden shifts in mood and attitudes, low frustration tolerance, task avoidance, and unpredictability. Frequently, these types of limitations are the most devastating in their impact on successful work adjustment and loss of income. People with AD/HD can learn the specific task requirements of a job, but cannot demonstrate job-related interpersonal skills, such as appropriate interactions with peers and supervisors, working collaboratively with others, accepting supervisory monitoring and criticism, and understanding acceptable types and levels of personal interaction.

Similar to the difficulties experienced in school when learning, the ability to work may be seriously impaired by deficits in attention, reasoning, and cognition, again due to deficits in executive functioning skills. These deficits may be evident in a variety of ways, including difficulties in concentrating and focusing on the task at hand; frequent shifting from one uncompleted activity to another; or the inability to physically remain in the same location for an extended period of time without fidgeting, feeling restless, or even fleeing the site. The individual with attention problems may be unable to “tune out” normal background noise and general conversation present in most workplaces, and as a result may become distracted, even agitated, and unable to work effectively.

Individuals who also experience deficits in processing, attention, memory, reasoning, or communication may experience a serious degree of cognitive fatigue as a result of expending additional effort and energy to compensate for these deficits. Physical and cognitive fatigue may result in a general decline in overall functioning as the work period progresses, demonstrated by lower productivity, increased mistakes and increased injury rate. Depending on the person's ability to handle and compensate for these deficits in the educational and work environments, performance may vary significantly from day to day.

The capacity to sustain an adequate level of work performance in pressure situations—such as project completion, shortened deadlines, or unexpected changes in job duties—may be significantly impaired in an individual with AD/HD. Such circumstances may require greater organization, increased speed, faster processing of information, and more focused attention, and such increased demands on already existing limitations may cause additional problems with frustration, anxiety, and consistency—and thus further limit the person's ability to carry out the tasks at hand.

## **CONCLUSION**

Research clearly indicates that in the vast majority of cases, individuals with AD/HD meet the criteria contained in the definition of developmental disability in the DD Act, and therefore are eligible for the services and programs provided for by the DD Act. Furthermore, work needs to be undertaken to reach consensus between individual agencies on who meets the definition of developmental disability, to prepare families to be able to successfully advocating on behalf of themselves and/or family members regarding their entitlement to services provided under the DD Act.

## NOTES

<sup>1</sup> Personal communication, (July 14, 2008). The CDC programs are national research initiatives and do not provide direct services and supports to eligible individuals.

<sup>2</sup> For example, Texas and Pennsylvania DD Councils both include AD/HD as an eligible disability, while Illinois has a more narrow definition.

<sup>3</sup> 42 U.S.C. § 15002 (8)).

<sup>4</sup> Faraone, Biederman, & Mick, 2006; Kessler, Barkley, Biederman, 2006.

<sup>5</sup> DSM-IV-TR, p. 85.

<sup>6</sup> DSM-IV-TR, p.85; Barkley, 2002.

<sup>7</sup> Barkley, 2006.

<sup>8</sup> Barkley, Fischer, Fletcher, & Smallfish, 2006; Weiss, Hechtman, *et al.*, 1985.

<sup>9</sup> 34 C.F.R. 361.5(b)(31).

<sup>10</sup> CDC, n.d..

<sup>11</sup> Barkley, 2006.

<sup>12</sup> Barkley, 2006.

<sup>13</sup> Barkley, 2006.

<sup>14</sup> Barkley, Murphy, Fischer, 2008; Snyder, 2001.

<sup>15</sup> Birnbaum, Kessler, Lowe, et al., 2005.

<sup>16</sup> Secnik, Swensen, & Lage, 2005.

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