

Disclosure in Educational Settings

by Susan Buningh, MRE, with Terry Illes, PhD, and Rob Tudisco, Esq.

DISCLOSURE OF AD/HD OR ANY OTHER HIDDEN DISABILITY is usually a matter of personal choice in situations throughout the lifespan. Disclosure takes on different dimensions in educational settings, however. Susan Buningh, MRE, Attention's managing editor, discussed the topic with two experts— Terry Illes, PhD, on the wisdom of parents' being open about their child's AD/HD in elementary and

secondary school settings, and Rob Tudisco, Esq., on the role of disclosure at the postsecondary level.



Terry Illes, PhD

Elementary and Secondary School Settings A chat with Terry Illes, PhD

A school psychologist in the Salt Lake City area for over twenty years, Terry Illes, PhD, is a former member of CHADD's board of directors and a current member of the editorial advisory board of Attention magazine. Illes is also one of the founders of CHADD's Parent to Parent program.

Some parents wonder whether their child with AD/HD should start fresh, with a "clear" record, when a new school year begins or the child transfers to a new school. They think perhaps they should wait and see whether the child "takes" to the new teacher, subject, or school. If the child does well, there's no need for the teacher to know about the child's AD/HD diagnosis. If the child doesn't do well, then they can disclose and request accommodations.

I understand the sentiment behind a "wait and see" strategy. It is natural for parents to be optimistic and to at least hope that the new school year will offer their child a new beginning untainted by the problems of the previous school year. After all, for the last fifty years, I have managed to convince myself each spring that this is the year that the Cubs will finally win the World Series. Nevertheless, this "wait and see" attitude is often counterproductive and naive. Although children with AD/HD may certainly improve over time, parents must keep in mind that the disorder is chronic and that the symptoms and associated impairments are unlikely to be remedied from one school year to the next. Unfortunately, parents who rely on a passive wait-and-see strategy, rather than on a more proactive and aggressive strategy of acting immediately, usually unnecessarily delay the implementation of essential interventions and supports for their child. This delay interrupts the continuity of services and fails to provide the consistency that makes such interventions durable and effective.

Moreover, it increases the likelihood that mild and manageable classroom problems are transformed into more severe and unmanageable problems.

Some parents worry that if they tell the classroom teacher their child has AD/HD, then the teacher will be biased toward their child. Although this risk cannot be completely dismissed, it is far less hazardous than the risk of withholding this information. A public school has a work climate like most others. Teachers discuss their students with colleagues, and over time it becomes common knowledge which students are the most challenging and difficult to teach. Thus, withholding information from a teacher does not guarantee that the teacher will not have a pre-impression of the child. As a result, the goal of a truly "fresh" start is often naive. More importantly, teachers who lack background information about a student's behavioral challenges are more likely to rely on false assumptions and explanations to understand the student's difficulties. Informed teachers are much more likely to have the foundation on which to build the critical supports needed to address the classroom problems of the student with attention deficits.

Why might parents choose not to disclose their child's AD/HD? Do teachers stigmatize children with AD/HD?

I also empathize with parents who are concerned that disclosing a child's diagnosis of AD/HD might label their child. There is no denying that the acronym—AD/HD—carries a lot of emotional meaning



and baggage. For many teachers, a student who has a diagnosis of AD/HD only means more work and frustration with no additional benefits. It is no wonder that parents are afraid that divulging their child's diagnosis might create resentment before the teacher even has the opportunity to form a relationship with the child. Nevertheless, as I noted above, withholding the diagnosis is more likely to inflame problems rather than prevent them.

When no background information is provided, teachers must guess as to the causes that underlie the problems the student is likely to experience within the classroom. The teachers might incorrectly decide that the student is lazy, unmotivated, attention-seeking, or undisciplined. These false explanations will lead the teachers to use ineffective interventions that often intensify rather than help ameliorate the student's behavioral problems. However, parents who inform teachers set the stage for open and effective collaboration between the home and school. When teachers feel that they have the support and trust of parents, they are more willing and able to go the extra mile for that student. And, without question, fostering a positive working relationship between the teacher and parents is the first and foremost step in creating a classroom environment in which the student with AD/HD can feel and be successful.



In your years of experience as a school psychologist, you must have seen what can happen when teachers are not fully informed about a child's challenges. Can you share an example of what can happen?

Unfortunately, this occurs far too often. Imagine a second-grade student with AD/HD at the onset of the new school year. The student's parents decide not to inform the teacher about their child's past problems in the hopes of offering their child a fresh start. Perhaps their child's problems were due to a personality conflict between their child and the teacher rather than to symptoms of AD/HD. They believe that the best method for testing this possibility is to wait and see what happens and assume that "no news is good news."

Unknown to the parents, the child begins to experience the same problems he or she did the previous year. Lacking other information, the teacher decides to implement strategies that have been effective with other students with behavior problems. Perhaps the student will eventually settle down and become accustomed to the class routine and his/her behavior will then improve. The teacher may be reluctant to contact the parents too quickly out of concern that the parents might react defensively and complain that the teacher has failed to provide their

> child with a fair chance to adapt to a new classroom setting.

> Meanwhile, the child's misconduct is intensifying and he or she is gaining a reputation as a troublemaker. Classmates are learning to avoid the student and are refusing to play with him/her during recess time. Moreover, the teacher is beginning to lose patience and has decided that the student is intentionally acting out to seek attention from classmates. Believing that attention-seeking is the reason for the misconduct, the teacher uses a punitive discipline style in an effort to manage the misconduct. This approach backfires, however, and the student's behavior problems become worse rather than better. By the time the teacher contacts the parents to schedule a conference, significant time has been wasted and a lot of damage must be undone. If the parents had been upfront with the teacher, effective supports for the child might have been implemented from the outset of the school year. Instead, the child now faces an uphill battle.



What are the advantages of disclosing that a child has AD/HD as early as possible, even before the school year begins?

There are many advantages of disclosure and, collectively, they provide the foundation for creating a nurturing and supportive classroom environment for the student with AD/HD.

- Disclosure creates an atmosphere of trust and promotes open communication between the parent and staff. When parents withhold information, it is almost impossible for the family and school to coordinate efforts to help the child. With disclosure, parents and staff may work together to identify the needs of the student and appropriate interventions.
- Disclosure provides a basis for collaboration between the school staff and the primary care physician. This helps the physician to develop an effective treatment plan.
- Disclosure often provides much needed information to determine the student's eligibility for special education and support services within the school setting.
- Disclosure provides a context for understanding the student's challenges rather than relying on inaccurate and misguided assumptionsabout the source of the student's challenges

Should parents worry about protecting their child's privacy? Can you comment on the school's responsibility with regard to confidentiality of the information that a student has AD/HD?

A child's diagnosis and treatment should be held in confidence and shared only with school personnel who are responsible for working with the child. It is particularly important that diagnosis and treatment issues are not discussed in the presence of other students to prevent the child with AD/HD from being embarrassed and humiliated in front of peers. I recommend that parents discuss this concern with the teacher at the beginning of each school year.

What advice would you give parents on teaching children about self-disclosing their AD/HD to their peers in school?

In general, more disclosure can be given with age. As students mature, they are likely to be more accepting and appropriate when such information is disclosed. However, more importantly, the child's own attitude about having AD/HD should dictate the extent and timing of the disclosure. The more comfortable and accepting the child is with the diagnosis, the more disclosure that can be expected. Children who are bothered and troubled by the diagnosis should not be forced to disclose to their peers regardless of their age. \blacksquare



Rob Tudisco, Esq.

Postsecondary Educational SettingsA chat with Robert Tudisco, Esq.

A student with AD/HD who needs reasonable accommodations in order to succeed in a postsecondary educational setting must first disclose the disability to appropriate individuals at the institution and submit sufficient documentation. Robert Tudisco, Esq., a practicing attorney who was diagnosed with AD/HD as an adult, sheds light on why disclosure is necessary under these circumstances.

How does the situation of a student with AD/HD change after graduation from high school?

Until graduation from high school, the burden is on the school district to seek out and identify children with disabilities and provide services and/or accommodations in order to guarantee a free appropriate public education (FAPE). After graduation, that burden shifts to the student with disabilities. In the postsecondary environment, it is incumbent upon the student seeking reasonable accommodations to disclose his or her disability at the earliest possible opportunity and self-report how it impairs learning. Only then must the school provide appropriate accommodations. This contrasts directly with the concept of "child find" in the Individuals with Disabilities Education Act (IDEA) and in Section 504 of the Rehabilitation Act of 1973.

So then early disclosure to the college, university, or other postsecondary educational institution is mandatory for students if they need accommodations. What information must the student have available—and what must the student disclose?

Even though AD/HD is recognized as a disorder that can cause disability under education and anti-discrimination legislation, having a diagnosis is only the first step to obtaining services and/or reasonable accommodations. The statutes that protect/apply to students with disabilities—Section 504 and the ADA—require the student to establish how the disorder impairs learning. It is the impairment, rather than the diagnosis, that triggers services and reasonable accommodations.

Section 504 and ADA both require that an individual with physical or mental impairment

show that the impairment "substantially limits" one or more major life activities. Thus, it's critical that parents and students are aware that an effective evaluation must do more than just diagnose a disability. A thorough evaluation should explain how a disability affects the ability to learn, and further what steps could be taken by way of services or reasonable accommodations to place the student on equal footing to those without disabilities. Accurate diagnosis is important, but only the first step to protection under the law.

If a student does not disclose a diagnosed disability up front, and then meets with academic difficulty or failure, can he or she later disclose and request accommodations? Why, in the postsecondary environment, is it inadvisable to wait and see whether accommodations are needed?

Recent case law illustrates how vital it is that postsecondary students with disabilities truly understand their special needs and articulate them to their schools as early as possible. Two lawsuits involving accommodations for postsecondary students under the

ADA were decided in July 2006. In both cases, the court stressed the importance of accommodations for students with disabilities under the ADA but found that neither plaintiff fit the criteria under the law.

The plaintiff in Steere v. George Washington University School of Medicine was a medical student with AD/HD and a learning disability in math who did not initially disclose his disabilities. After he failed some classes, the school allowed him to retake them. Following subsequent failures, the dean of the medical school dismissed him and refused to consider his new evidence of a disability. Evidence of the diagnosis of AD/HD and math learning disability was offered only after the student began having academic difficulties. The court accepted AD/HD as a legitimate disability that in some cases can qualify a student for accommodations under federal law, but held that the plaintiff failed to show how his particular AD/HD and learning disability impaired him in pursuing a "major life activity," criteria required for protection under ADA.

The plaintiff in the companion case, Singh v. George Washington University School of Medicine, had also been allowed to retake courses she initially had failed. When her academic progress did not meet school standards, she was called before a medical student evaluation committee to determine whether the school should recommend dismissal. During the proceedings, she sought testing to determine whether she might have a learning impairment. She subsequently produced a report from a psychologist stating that she had a reading disorder and a mild processing-speed disorder. The dean reviewed the report, but did not change his recommendation for dismissal. After reviewing the evidence at trial, the court did not find that the plaintiff had a disability as defined by the ADA.

What do these cases mean for students with AD/HD and related disorders?

The significance of these cases is twofold. Both decisions clearly indicate that the students did not self-report their disabilities at the earliest possible opportunity, a crucial component of the protections for postsecondary students under both the ADA and Section

504. The court's ruling stresses the importance for the student to self-report disabilities and seek accommodations in order to enjoy protection under the ADA. Parents and students must understand this, and foster and develop self-advocacy at the earliest possible age. Students entering the postsecondary educational environment must be able to understand their disability, report it to the school, provide current documentation, and request appropriate accommodations.

The second issue raised by these cases is the requirement under the ADA and Section 504 that the student articulate how the disability specifically impairs a "major life activity." The plaintiff in Steere in particular failed to do this. The court essentially stated that a diagnosis of AD/HD, or any other learning disability, is not enough in and of itself to establish a claim under the ADA. This underscores again the necessity for students to understand their disability and how it affects their ability to learn—not only so that the student can request appropriate accommodations, but also to justify the necessity of those accommodations in a claim under the ADA.

In the postsecondary environment, it is incumbent upon the student seeking reasonable accommodations to disclose his or her disability at the earliest possible opportunity and self-report how it impairs learning. Only then must the school provide appropriate accommodations.

