

The Quest for Recognition of AD/HD Within the IDEA: A Case Study in Public Policy Advocacy, Perseverance, and Grassroots Effort

Since the passage of Public Law 94-142 (then called the Education for All Hand-icapped Children Act, and now called the Individuals with Disabilities Educa-tion Act) in 1975, children with disabilities have been eligible to receive special education ser-vices in the United States if, and only if, they were determined to be eligible for special edu-cation services because they met the eligibility criteria for one of the categories of disability specified in the law. Unfortunately, Attention Deficit Disorder and Attention Deficit Hyperac-tivity Disorder were not specifically listed in either the statute or the regulations that imple-ment the statute. Because school districts have been focussed on the eligibility categories as a basis for service, this has meant that many schools believed that AD/HD was not covered under the special education law.

As a result, some children who were in need of services were served under Section 504 of the Rehabilitation Act of 1973 instead, while others were not provided special education services, accommodations, or the legal protections that go with these laws. Moreover, because of the absence of legislative clarity as to where AD/HD fit, where a child lived became a major variable in determining whether or how they received services to address AD/HD. For over two decades, this has resulted in many children being denied adequate services and protections or any services at all.

Leading the Fight

Beginning in the late 1980s, shortly after CHADD was formed, the organization started working to rectify this situation. Initially, a legislative effort was mounted by CHADD in the United States Congress to try to get AD/HD listed as a disability category. This included visits to Congress by a number of CHADD pioneers, including Dr. Harvey Parker, Mary Fowler, and Sandy Thomas (who were early leaders in CHADD), Dr. Russell Barkley, Dr. Jim Swanson, Dr. Hugh Leichtman, Dr. Bennett Shaywitz, and Dr. Alan Zametkin (who are all preeminent researchers in the field of AD/HD). Pam Murray, from Colorado, was also involved in some of these early efforts. Legislation was introduced by the late Congressman Silvio Conte to add AD/HD as a separate category. This legislation was met by substantial opposition from many groups, including some of the major educational organizations. Mary Fowler and others met with some of these groups to try to counteract their opposition. Finally, the bill passed the House, but was ultimately defeated in the Senate. However, it did lead to a compromise in which the U.S. Department of Education was ordered by Congress to issue a Letter of Inquiry concerning AD/HD and whether it should be listed as a disability under the special education laws.

CHADD, with the assistance of its legal counsel, David Aronofsky and Elliott Portnoy, mounted a national letter writing campaign to communicate to the U.S. Department of

Education the problems families were having in getting services for their children with AD/HD. This effort paid off when, in September of 1991, the Department issued an unprecedented joint memorandum from the assistant secretaries of the Department who were responsible for the administration of the EAHCA (now IDEA) and Section 504. This joint policy memorandum concluded that AD/HD did not need to be listed in the statute because it was already covered under existing categories. According to the policy letter, even if a child did not meet the eligibility criteria due to a learning disability or serious emotional disturbance, the child could qualify for special education within the category called "Other Health Impaired" if the child had been determined to have AD/HD to an acute degree and over a prolonged period of time, which resulted in limited alertness and adversely affected educational performance such that special education services were needed. The policy letter also reiterated the Department's prior position that AD/HD was covered under Section 504 if it substantially limited learning and required special education OR related services. (Related services can include such activities as the administration of medication by a school nurse).

Confronting Setbacks

While CHADD welcomed the issuance of the 1991 policy letter, it quickly became clear that AD/HD was not neatly covered by the Other Health Impaired Language regarding "limited alertness" – many children with AD/HD had the opposite problem, to wit, being excessively alert to everything going on. In 1993, in response to a letter of inquiry addressing this question, the Department issued a clarification of the 1991 policy memorandum. The clarification indicated that the OHI criterion requiring limited alertness on the part of a child with AD/HD was satisfied if the child demonstrated limited alertness to academic tasks due to heightened alertness to environmental stimuli. (Letter to Cohen, 20 IDELR 73(5/13/93)).

At the same time, the Department issued other policy letters clarifying that a doctor's diagnosis was not required, but that if a school chose to require a doctor's evaluation, it must be provided at no cost to the parent. (Letter to Parker, 18 IDELR 963 (2/18/92)). Unfortunately, while the 1991 policy letter and subsequent legislation were a step in the right direction, many school districts, whether due to ignorance or a deliberate policy decision, chose to continue to exclude children with AD/HD from special education eligibility. While not all children with AD/HD need special education, and many do not meet the criteria for eligibility, many children with AD/HD who would meet the criteria were denied the services and legal protections to which they were entitled. For many children with AD/HD, this meant that school was a place of even greater difficulty, undoubtedly increasing the likelihood of school failure, behavioral difficulties, and dropping out.

Redirecting Efforts

In 1995, the IDEA was scheduled to be reviewed and reauthorized by Congress. Initially, CHADD leadership and members of the Government Relations Committee (including Joanne Evans, Sheila Anderson, Mary Robertson, Maureen Gill, Marlene

Snyder, Elliott Portnoy, Sheila Lachs, and myself) hoped that this would present an opportunity for AD/HD to be added to the list of covered conditions. Unfortunately, three powerful political realities competed against this strategy. First, the Department of Education was lobbying to shift away from the categorical model altogether, and it appeared it would be difficult to gain their support for an additional category when they were pushing for a non-categorical system. Second, Congress was under enormous pressure from many school systems to roll back many of the substantive and procedural protections contained in the IDEA; that is, to dilute the law's protections for all children with disabilities. It seemed inopportune to push for more children to be included when the disability community was fighting to save that which we already had. Finally, there was a tremendous backlash against the special safeguards contained in IDEA with respect to the discipline of students with disabilities. Given that children with AD/HD are more vulnerable to disciplinary problems, it was unwise to push for the controversial safeguards to be extended even further.

As a result, CHADD redirected its legislative efforts towards protecting desired portions of the law, fending off some of the measures intended to limit the scope of the law, and offering legislative initiatives to respond to some of the identified problems in a positive rather than reactionary manner. In the end, the law, which passed Congress in the Spring of 1997 and was signed by President Clinton on June 4, 1997 (CHADD representatives were invited to the signing ceremony) was substantially preserved. Notably, CHADD played a very active role in the legislative process. The CHADD leadership and Government Relations Committee working on this project included Carl Smith, Dean Rivkin, Julia Bell, Joanne Evans, Sheila Anderson, Mary Robertson, Elliott Portnoy, and myself. In addition, dozens of CHADD members wrote letters and contacted their Congressmen and Senators. Ultimately, CHADD and other disability groups succeeded in getting some of the most onerous measures, particularly concerning discipline, replaced with provisions that required schools to look at each child's behavior individually and to focus on positive behavioral interventions, rather than exclusion. For example, CHADD proposed much of the language that eventually was incorporated in the IDEA within the section dealing with "manifestation determination." Our efforts helped in formulating the final wording that requires a careful review of the appropriateness of what has been planned and provided for a student before a determination of a student's individual responsibility in disciplinary matters is made. CHADD also moved forward with a position paper on issues regarding the discipline of students with AD/HD that has been used to help define what we believe are the most important protections to be afforded for students with AD/HD facing disciplinary measures.

Yet, with all of these positive advocacy accomplishments, we still needed to deal with the eligibility issue. After a law passes, the executive branch is then charged with issuing formal regulations to implement the law. These regulations are given the force and effect of the law and are binding on those who they effect. After the passage of IDEA '97, CHADD concluded that the adoption of the regulations implementing IDEA presented an opportunity to secure recognition for AD/HD within the regulations. To accomplish this, CHADD mounted a campaign to secure information from parents and

schools documenting both the problems that are presented when children with AD/HD are improperly denied eligibility altogether and when they are provided eligibility under Section 504. A letter writing campaign was initiated by the Government Relations Committee, encouraging CHADD members throughout the U.S. to write to the Department of Education.

The Department organized hearings throughout the country to take testimony from interested parties. Through the efforts of Sheila Lachs, who was then CHADD's Government Relations Director, CHADD had members testify at every one of the nine hearings around the country. CHADD leaders also met with key Washington policy makers on a continuing basis in an effort to maintain support for the inclusion of AD/HD. We have been informed that the collective efforts of CHADD members, the Government Relations Committee, and Laurel Stine, who replaced Sheila Lachs as CHADD's Government Relations Director, led to more letters and more people testifying about AD/HD than on any other issue concerning the proposed regulations. Equally important, we have been informed that the testimony of CHADD members was powerful in documenting the problems encountered by children with AD/HD.

Celebrating the Victory

Through the fall and into the spring, we waited for the final regulations to be issued. Finally, on March 11, 1999, they were issued. AD/HD was formally listed in the regulations for the first time, under the category "Other Health Impairment." The new language states: "Other Health Impairment means having limited strength, vitality or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that:

(i) is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, and sickle cell anemia; and

(ii) adversely affects a child's educational performance."

The addition of AD/HD within the OHI category represents a huge step forward in achieving recognition from the schools. Schools will no longer be able to argue that AD/HD is not a covered condition. In their planning, they will now be required to address AD/HD systemically and systematically, rather than in a reactive manner or by deflection. At the same time, there is now much to be done in educating schools and parents that AD/HD is covered and to assist schools in developing appropriate strategies for meeting the needs of children with AD/HD. While this does not solve all the problems encountered by children with AD/HD at school, it does mean that AD/HD is now part of what schools are required to deal with and accommodate for.

CHADD's efforts in accomplishing this recognition reflect years of work by hundreds of individuals. In fact, I have undoubtedly left out a number of key individuals, for which I

apologize. Our success illustrates the importance of national, state, and local efforts working together in a coordinated fashion towards a common goal. Indeed, it is a lesson for what we must now undertake to translate this new recognition into a working reality that is meaningful for children with AD/HD. To all of you who contributed, in whatever way, thank you for your efforts.

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