Children and Adults with Attention-Deficit/Hyperactivity Disorder Public Policy Agenda for Children 2008 – 2009

Accepted by the Board of Directors October 31, 2008

Introduction

CHADD (Children and Adults with Attention-Deficit/Hyperactivity Disorder) is committed to improving the lives of individuals with AD/HD and represents individuals of all ages with AD/HD, their families, and the professionals who work with them. In support of the organization's public policy advocacy, CHADD's Public Policy Committee and Board of Directors annually determine major policy initiatives for children and adults, setting policy parameters and guiding advocacy efforts to the extent permitted by CHADD's finite resources.

CHADD's advocacy activities are founded and focused on three broad goals:

1. Promoting scientific research on AD/HD,

2. Increasing access to effective, evidence-based, interventions, treatments and practices for diverse populations with AD/HD across the lifespan, and

3. Protecting and enhancing the civil rights of individuals with AD/HD, to ensure that all children and adolescents with AD/HD receive equal and appropriate rights, protections and opportunities in all aspects of society, including: education, employment, juvenile and criminal justice, healthcare, emergency management, community access and housing.[1]

Background

A 2005 Centers for Disease Control and Prevention (CDC) report found that parents reported approximately 7.8% of school-age children (4 to 17 years) had a history of AD/HD diagnosis and that about half of these (4.3%) were treated with medication.[1] Other studies show that more than 70% of children with AD/HD will continue to experience symptoms of AD/HD into adolescence, and almost 65% will exhibit AD/HD characteristics as adults. In addition, as many as two-thirds of children with AD/HD have at least one co-existing condition.[2] If untreated or inadequately treated, AD/HD can have serious consequences, increasing an individual's risk for school failure, unemployment, interpersonal difficulties, other mental health disorders, substance and alcohol abuse, injury, antisocial and illegal behavior, contact with law

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[1] In this context, housing refers to any facility that an individual with AD/HD resides during the night hours. This can include, but is not limited to, juvenile justice facilities, residential homes, private schools and other entities designed to manage behavior such as "bootcamps".

enforcement, and shortened life expectancy.[3] Appropriate services and treatment can help individuals with AD/HD avoid negative outcomes and lead successful lives. A number of national organizations recognize AD/HD as a condition that can significantly impair an individual's functioning at work, at school, or in society.

CHADD's Public Policy Agenda for 2008-2009 is also aligned with recommendations for improving mental health treatment and services contained in a series of national reports on mental health. The organizations recognizing AD/HD are listed in Appendix A, while Appendix B contains a list of national reports.

Goal #1: Promoting scientific evidence-based research on AD/HD

1. **Research Funding** – CHADD supports broadening and funding the national research agenda addressing:
    - Prevention and early identification,
    - Research on the causes, diagnosis, and treatment of AD/HD across the lifespan,
    - Safety and effectiveness of AD/HD treatments, including medication (especially for children and adolescents), and short- and long-term effects
    - Effectiveness of therapies,
    - Effectiveness of educational, psychosocial and various alternative interventions.

2. **Long-Term Outcomes** – CHADD supports research on the long-term impact of AD/HD and co-existing disorders on:
    - Psychosocial, behavioral, educational outcomes,
    - Employment,
    - Financial status,
    - Health outcomes, including the long-term impact of treatment options.

3. **Diversity** – CHADD supports requiring publicly funded research efforts to include diverse populations, as appropriate, with respect to gender, sexual orientation, race/culture, and age.

4. **Research on Emerging Practices –** CHADD supports increased research on emerging practices, such as AD/HD Coaching, neuro-feedback, and other interventions. If effective practices are recognized, CHADD also supports setting minimum standards for such practices, for the benefit and protection of recipients of these services.

5. **Dissemination of Research –** CHADD supports the fact that researchers have a special obligation to disclose the sources of funding of their research because the entire profession depends upon their findings to make determinations about treatment for patients.

Therefore, CHADD supports full public financial transparency and disclosure of all funding sources of such researchers, including full public disclosure of all external funding and in-kind support to researchers, whether or not related to the specific research project. Further, researchers should publicly disclose stock or other interest they hold in any entity involved in the field of their research.

Goal #2: Increasing Access to Effective Interventions, Treatments and Practices

Access in Education

1. **Multimodal Treatment** – CHADD supports legislation and regulations that ensure access to multi-modal treatment at school for students with AD/HD, regardless of disability classification, including:
    - The use of effective, evidence-based, mental health, behavior-management and academic interventions;
    - Increased communication and collaboration among educators, families, and medical or mental health professionals to address learning and behavior problems;
    - Provisions for appropriate administration of prescribed medications at school;
    - Development and provision of quality school-based mental health programs.

2. **Free and Appropriate Public Education** – CHADD supports preserving and strengthening provisions in special education and disability laws and regulations that protect the right of students with disabilities to free appropriate public education (FAPE), in the least restrictive environment (LRE) appropriate for the child, including students with disabilities who have been suspended or expelled from school. CHADD also supports administrative and judicial interpretation expanding, rather than curtailing, the rights of children and adolescents with AD/HD. CHADD opposes the application of provisions which make it more difficult for parents to pursue due process and legal rights and support mechanisms to increase the ability of parents to secure free or low-cost representation.

3. **Student Progress** - CHADD supports maintaining education services that ensure access to and progress in the general curriculum for students with disabilities through the development of validated assessments, including:
    - Comprehensive evaluation and assessment of learning disabilities and behavioral needs by skilled examiners that leads to accurate diagnosis of learning disabilities, AD/HD and other conditions.
    - Individualized education;
    - Appropriate accommodations, modifications, and supplemental and related services;
    - Continuing applicability of Section 504 and IDEA protections for eligible children and adolescents with AD/HD and other related disabilities.
    - Measurement of curriculum-based monitoring.

4. **AD/HD as a Qualifying Condition in "Other Health Impairment"** – CHADD supports continued recognition of AD/HD as a qualifying condition in the Other Health Impairment (OHI) category of IDEA, while advocating a more inclusive and explicit definition for AD/HD via regulation or statute to ensure appropriate evaluation and/or services.

5. **Positive Behavioral Supports** – CHADD supports developing, implementing, and enhancing school-wide positive behavioral supports and interventions, as well as individually implementing supports and interventions for students with disabilities who exhibit challenging behaviors.

6. **Disciplinary Actions** – CHADD supports maintaining procedural safeguards, improving disciplinary practices, and monitoring the effects of laws and policies on disciplinary outcomes for students with AD/HD, as well as promoting measures which emphasize positive interventions and supports, rather than punitive procedures or criminal prosecution.

7. **Educator Training** – CHADD supports pre-service and in-service training on AD/HD for all school staff, including administrators, teachers, counselors, nurses, and related services providers. Training should focus on research-based information and best practices in relation to the disorder, including:
    - Identification, evaluation, and treatment;
    - Impact on student performance and behavior;
    - Effective, culturally relevant, academic and behavioral interventions and strategies that help children and adolescents with AD/HD succeed in school.

8. **Federal Funds for Special Education** – CHADD supports securing 40% federal funding match for special education while maintaining the current non-supplanting provisions.[2]

9. **Accountability for Special Education –** CHADD supports the need for further accountability regarding the spending of funds designated for special education and related services.

10. **Open Communication Between Families, School Staff and Appropriate Professionals** – CHADD supports open communication between school staff and parents regarding any behavior(s) of concern in the classroom, the need for evaluation for a possible disability and feedback on a child's performance in the classroom after any interventions, including medication. CHADD strongly opposes any effort to restrict open communication between school staff members and parents.

11. **Early Intervening Services** – CHADD supports the newly established Early Intervening Services (EIS) program for students in need of additional academic and behavioral support in order to succeed, CHADD supports developing regulations delineating timelines and criteria for determining when EIS services are insufficient and when a child should be referred for evaluation for appropriate special education services under IDEA. CHADD supports insuring that parents are fully included in the decision to utilize EIS services for a particular student, in the development of the service plan and evaluation procedure for the intervention, and in the timeline for the intervention. Parents should retain the right to seek evaluation for special education eligibility at any time and should be advised of this right if their child is being referred for EIS services.

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[2] The IDEA currently requires that all federal funds provided to local school districts to support special education be used to supplement the state and local funds allocated for special education, rather than to replace them. This rule was put into place to assure that the federal funds would be used to increase available funds for special education, rather than to indirectly allow the schools to reduce their own spending for special education. This rule is called the "non-supplanting" rule. Some proposals have called for repeal of the non-supplanting rule, thereby allowing schools to decrease their own spending on special education in proportion to the increased funding they received from the federal government under IDEA, resulting in zero increase in funding for special education programs.

Access in Healthcare

1. **Multimodal Treatment** – CHADD supports the alignment of physical and mental healthcare in a coordinated and efficient system that uses state-of-the-art health information technology using privacy-protected and consumer-centered electronic medical records. CHADD further supports policies that provide access to the full range of treatment options recommended for multimodal treatment of AD/HD and co-existing disorders, including:
    - Screening, early assessment and treatment
    - Health care services
    - Mental health services
    - Medication
    - Behavioral and academic interventions
    - Substance abuse treatment
    - Parent/family education and training

    CHADD supports the fact that all children and adolescents should have access to the quality and routine healthcare services they need, and those services should be affordable, community-based, and culturally sensitive treatment and services options for all individuals with AD/HD and their families regardless of their ability to pay for services out-of pocket.

2. **Underserved Populations** - CHADD supports policies that ensure adequate health care for culturally diverse and other underserved populations (e.g., girls) and that rectify treatment disparities for racial and ethnic minorities.

3. **Knowledge Dissemination** – CHADD supports the growth of publicly funded centers that provide research-based information to families, educators and health care professionals, such as the Centers for Disease Control and Prevention's program on AD/HD. Such efforts should also target the needs of underserved populations, including minorities and those who live in rural areas.[3]

4. **Full Parity** – CHADD supports the establishment of policy providing full parity between mental health care and physical health care insurance coverage.

5. **Access to Affordable Diagnosis, Treatment and Medication–** CHADD opposes any regulation or legislation that would limit, restrict or undermine the ability of medical and mental health care professionals to provide or prescribe appropriate treatment

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[3] CHADD supports the recommendations in the *Bill of Rights for Children with Mental Health Disorders and their Families*, which was created by a coalition supporting children's mental health and facilitated by the American Academy of Child and Adolescent Psychiatry (AACAP).

interventions, including medication. CHADD supports policies ensuring access to affordable diagnosis and treatment, where appropriate, and providing pharmacy benefits for medications used to treat AD/HD in all public and private health insurance programs. CHADD also supports efforts to ensure access to effective medications that were previously denied due to restrictive health plan formularies.

6. **Community Based Services** – CHADD supports legislative efforts to further develop and maintain family-centered, community-based, health and mental health services and supports, including substance abuse treatment and services including models of care that encourage primary and preventative care, such as medical homes and wellness programs.

7. **Qualified Health Care Workforce** – CHADD supports policies that develop and ensure an adequate workforce of qualified health care personnel, well trained in the identification, evaluation, and treatment of AD/HD, its impact on child performance and behavior, and effective research-based interventions, such as medication, where appropriate, and behavioral management.

Goal #3: Protecting and Enhancing the Civil Rights of Individuals with AD/HD

1. **Promotion and Preservation of Civil Rights of Individuals with Disabilities** – CHADD supports protecting and enhancing the civil rights of children and adolescents with disabilities and their families through such federal statutes, including but not limited to, the Americans with Disabilities Act (ADA), the Individuals with Disabilities Education Act (IDEA), and Section 504 of the Rehabilitation Act, and through actions to ensure that such laws are reauthorized, strengthened, funded and vigorously enforced and redressing judicial interpretations that have limited their scope.

    - **Reasonable Attorney Fees -** CHADD supports laws reinstating the right to recover fees for prevailing plaintiffs in settlements of special education and civil rights cases and preserving the right of prevailing plaintiffs to recover attorney fees in special education and civil rights cases. CHADD supports amending IDEA to allow for recovery for expert witness fees for a prevailing parent.

    - **Disparate Treatment** – CHADD supports legislative and judicial efforts to address disparate treatment of children and adolescents with disabilities within the areas of public education, juvenile justice, and health care programs. CHADD supports the inclusion of AD/HD and other neurobiological disorders in the definitions/eligibility categories for government benefits programs such as SSI, SSDI, Medicaid, developmental disability, and vocational rehabilitation programs.

Protecting Civil Rights within the Juvenile Justice System

1. **AD/HD and the Juvenile Justice System** - CHADD supports greater awareness and understanding by the public and policymakers of the impact of AD/HD on behavior and its relation to co-existing disorders (e.g., conduct disorder, bipolar disorder, substance abuse, and other forms of mental illness) that may increase an individual's risk for contact with the justice system.

2. **Mental Health Courts -** CHADD supports expanding the Mental Health Court model to include juveniles, so that children and adolescents with AD/HD, co-existing disorders, and other forms of mental illness receive appropriate treatment, support, and services for successful rehabilitation.

3. **Office of Juvenile Justice and Delinquency Prevention** - CHADD supports expanding current efforts by the Office of Juvenile Justice and Delinquency Prevention and the Coalition for Juvenile Justice to assess and reduce the prevalence and impact of AD/HD and related disorders among children and adolescents within the juvenile justice system.

4. **Right to Education and Health Care –** All children and adolescents with AD/HD and other co-occurring disorders in the juvenile justice system have the right to receive a free, appropriate public education and multimodal treatment, including access to health and mental health services.

5. **Equal Rights and Protections** – CHADD supports policies that ensure children and adolescents with AD/HD are afforded equal rights and protections and are assured access to appropriate accommodations, modifications, and services throughout the legal process and within the justice system.

6. **AD/HD as a Factor in Disposition** – CHADD supports increased awareness and recognition within the justice system, including judges, prosecutors, defense attorneys, law enforcement, and probation officers of the impact of AD/HD on a defendant's ability to make appropriate choices and to control impulses and emotions, and increased consideration for AD/HD as a contributing and/or mitigating factor, with a focus on preventing any antisocial activity from recurring in the future.

7. **Training on AD/HD** – CHADD supports greater awareness and understanding by law enforcement, corrections, prosecutors, defense attorneys, and justice personnel about AD/HD through increased funding for personnel training, including:
   - Impact on behavior;
   - Related disorders;
   - Development and dissemination of written materials on best practice models and effective programs.
   - CHADD supports the development and delivery of curricula in law schools and continuing education for attorneys to ensure greater awareness and understanding of AD/HD, co-existing disorders, and other forms of mental illness that may increase an individual's risk for contact with the justice system.

8. **Safeguards against Unintended Consequences of Sexual Predator Legislation –** While CHADD supports legislation designed to protect individuals from sexual predators, CHADD also supports language that will not unfairly target children and adolescents with AD/HD from being erroneously classified as sexual predators. CHADD also supports language that would distinguish between "offenders" and "predatory behavior."

Conclusion

This Agenda defines the current areas of interest of the Public Policy Committee and CHADD's Public Policy staff. Within these parameters, and subject to the restrictions and definitions of the Tax Reform Act of 1976, CHADD will work to promote national activities beneficial to individuals with AD/HD. As unanticipated issues arise requiring prompt action, the President and Chief Executive Officer and the Chair of the Public Policy Committee (in consultation with the Executive Committee when possible) will act in accordance with the organization's Goals and Objectives as established in CHADD's Strategic Plan and in accordance with the policies of CHADD. The Board of Directors shall be advised of all such actions at the earliest possible time.

References:

1. US Centers for Disease Control and Prevention (2005). Mental Health in the United States: Prevalence of Diagnosis and Medication Treatment for Attention-Deficit/Hyperactivity Disorder.
2. Dulcan, M., and the Work Group on Quality Issues. (1997, October). AACAP official action: Practice parameters for the assessment and treatment of children, adolescents, and adults with Attention-Deficit/Hyperactivity Disorder. *Journal of the American Academy of Child and Adolescent Psychiatry, Supplement, 36*(10), 85S-121S.
3. Barkley, R. A. (1997). *ADHD and the nature of self-control*. New York, NY: The Guilford Press.
4. U. S. Department of Health and Human Services. (1999). *Mental health: A report of the Surgeon General*. Rockville, MD: U. S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health.
5. U. S. Department of Health and Human Services. (2000). *Report of the Surgeon General's conference on children's mental health*. Rockville, MD: U. S. Department of Health and Human Services, U. S. Department of Education, and the U. S. Department of Justice.
6. U. S. Department of Health and Human Services. (2001). *Mental health: Culture, race, and ethnicity-Supplement to Mental health: A report of the Surgeon General*. Rockville, MD: U. S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health.
7. Children's Behavior Alliance. (2003). *In the best interests of all*. Landover, MD: CHADD.
8. New Freedom Commission on Mental Health. (2003). *Achieving the promise: Transforming mental health care in America: Final report.* Rockville, MD: U. S. Department of Health and Human Services.
9. School Mental Health Alliance. (2005). *Working Together to Promote Academic Performance, Social and Emotional Learning, and Mental Health for All Children. New York, Center for the Advancement of Children's Mental Health at Columbia University.*

Appendix A:
National Organizations and Major Reports Supporting Treatment of AD/HD

A number of national organizations recognize that AD/HD is a condition that can significantly impair an individual's functioning at work, at school, or in society.

- American Academy of Pediatrics
- American Academy of Child and Adolescent Psychiatry
- American Association of School Psychologists
- American Medical Association
- American Psychiatric Association
- American Psychological Association
- Centers for Disease Control and Prevention
- Center for Mental Health Services
- National Association of Social Workers
- National Institute of Mental Health
- President's Commission on Excellence in Special Education
- Surgeon General of the United States
- U. S. Department of Education

Appendix B:
National Reports Recommending Improvements in Mental Health Treatment

CHADD's Public Policy Agenda for 2008-2009 is aligned with recommendations for improving mental health treatment and services contained in a series of reports on mental health, including:

- *Mental Health: A Report of the Surgeon General (1999)*[6]
- *Report of the Surgeon General's Conference on Children's Mental Health* (2000)[7]
- *Mental health: Culture, race, and ethnicity-Supplement to Mental health: A report of the Surgeon General* (2001) [8]
- *In the Best Interests of All* (2003)[9], the position paper of Children's Behavior Alliance;
- *Achieving the Promise* (2003),[10] the report of the President's New Freedom Commission on Mental Health,
- *Working Together to Promote Academic Performance, Social and Emotional Learning, and Mental Health for All Children* (2005)[11], the position paper of the School Mental Health Alliance.