

# **Children and Adults with Attention-Deficit/Hyperactivity Disorder Public Policy Agenda for Adults 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, and to ensure that all adults 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<sup>1</sup>.

## **Background**

Studies show that more than 70% of children with AD/HD 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 those with AD/HD have at least one co-existing condition.<sup>1</sup> 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 enforcement, and shortened life expectancy.<sup>2</sup> Appropriate services and treatment can help individuals with AD/HD avoid negative outcomes and lead successful lives.

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<sup>1</sup> 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, criminal justice facilities and residential programs.

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 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 for:
  - Research on the causes, diagnosis, and treatment of AD/HD across the lifespan,
  - Safety and effectiveness of medication, as well as long-term effects,
  - Effectiveness of therapies,
  - Educational, vocational, 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, race/culture, sexual orientation 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 standardization, 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. Furthermore, 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 Employment**

1. **Protection from Employment Discrimination** – CHADD supports preserving, enhancing, and vigorously enforcing laws and policies that ensure civil rights protections, reasonable accommodations, training, and support for adults with AD/HD and other disabilities as mandated in the Americans with Disabilities Act, Section 504 of the Rehabilitation Act and state law.
2. **Employer Education** – CHADD supports the provision of information and training for employers on AD/HD and the establishment of reasonable accommodations in the work place, therefore reducing the existing stigma.
3. **Military** – CHADD supports eliminating discriminatory restrictions on enlistment by adults with AD/HD in the military and supports access to appropriate treatment for individuals with AD/HD in the military.

### **Access in Healthcare**

1. **Recognition of AD/HD in Adults** – CHADD supports recognition of AD/HD as a disorder affecting adults in diagnostic manuals, guidance and public policy.

2. **Access to Multimodal Treatment in Health Care** – 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 adults access to the full range of treatment options recommended for multimodal treatment of AD/HD and co-existing disorders, including:

- Health care services
- Mental health services
- Medication
- Behavioral and academic interventions
- Substance abuse treatment

CHADD supports the fact that all adults should have access to the quality 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 these services out-of pocket.

3. **Underserved Populations** - CHADD supports policies that ensure accurate and timely diagnosis, and research-based treatment for people with AD/HD, especially for culturally diverse and other underserved populations (e.g., women) and policies that rectify treatment disparities for racial and ethnic minorities.

4. **Access to Treatment and Medication** – CHADD opposes any efforts that would limit, restrict or undermine the ability of medical and mental health care professionals to provide or prescribe appropriate treatment, including medication. CHADD supports policies ensuring access to affordable medications, 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 previously were denied due to restrictive health plan formularies. CHADD opposes any formulary restrictions for effective medications.

5. **Knowledge Dissemination** – CHADD supports the growth of publicly funded centers that provide research-based information to families, educators, employers 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, women, and those who live in rural areas.

6. **Full Parity** – CHADD supports the establishment of policy providing full parity between mental health care and physical health care insurance coverage.
7. **Community-Based Services** – CHADD supports legislative efforts to further develop and maintain client-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.
8. **Qualified Health Care Workforce** – CHADD supports training and policies that develop and ensure an adequate workforce of qualified health care personnel who are well-trained in the identification, evaluation, and treatment of AD/HD, its impact on performance and behavior, and effective research-based interventions for adults such as medication, where appropriate, and behavioral management.

#### **Access to Disability Benefits and Services**

1. **Recognition of AD/HD** – CHADD supports legislative, judicial and public recognition of AD/HD as a disabling condition affecting adults, and supports full and equal access to government benefits and programs and equal protections of the civil rights laws for individuals with AD/HD and with AD/HD and co-occurring conditions.

#### **Access to Post-Secondary Education and Professional Training**

1. **Disability Services** - CHADD supports maintaining education services in post-secondary institutions that ensure access to and progress in the general curriculum, including:
  - Comprehensive evaluation and assessment of learning and behavioral needs;
  - Individualized education;
  - Appropriate accommodations, modifications, and supplemental and related services.
  - The continuing applicability of Section 504 and ADA protections for eligible students with AD/HD.
2. **Educator Training** – CHADD supports pre- and in-service training on AD/HD for all faculty, including research-based information about the disorder and its identification, evaluation, and treatment; its impact on student performance and behavior; and effective, culturally relevant, academic and behavioral interventions and strategies that help individuals with AD/HD to succeed in college.

- 3. Qualifying and Licensing Exams** - CHADD supports the reasonable provision of accommodations for students with AD/HD and other disabilities on college and graduate school entrance exams and on various national and state licensing exams. CHADD opposes restrictions on accommodation for such examinations that unfairly exclude individuals that were diagnosed as adolescents or as adults.

**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 adults with disabilities and their families through such federal statutes, including but not limited to, the Americans with Disabilities Act (ADA), and Section 504 of the Rehabilitation Act, and through actions to ensure such laws are reauthorized, strengthened, funded and vigorously enforced and redressing judicial interpretations that have limited their scope.
  - **Disparate Treatment** - CHADD supports legislative and judicial efforts to address disparate treatment of adults with disabilities within the areas of public education, criminal justice and health care. 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 Criminal Justice system**

- 1. AD/HD and the Justice System** – CHADD supports the development of 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. 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.

3. **Assessment of the Prevalence of AD/HD in Justice Systems** – CHADD supports efforts to accurately assess the prevalence of AD/HD and related disorders among individuals who are being prosecuted or incarcerated.
4. **Right to Health Care** – CHADD supports the right of all adults with AD/HD and other co-occurring disorders who are defendants or prisoners in the criminal justice system to receive appropriate multimodal treatment in health care.
5. **Equal Rights and Protections** – CHADD supports policies that ensure that individuals with AD/HD are afforded equal rights and protections and have access to appropriate accommodations and modifications throughout the legal process and within the justice system.
6. **AD/HD as a Factor in Disposition** – CHADD supports the development of increased awareness and recognition within the justice system 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.

### **Conclusion**

This Agenda defines 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. 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.
2. Barkley, R. A. (1997). *ADHD and the nature of self-control*. New York, NY: The Guilford Press.

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

## **Appendix B:**

### **National Reports Recommending Improvements in Mental Health Treatment**

CHADD's Public Policy Agenda for 2006 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)*<sup>6</sup>
  - *Report of the Surgeon General's Conference on Children's Mental Health (2000)*<sup>7</sup>
  - *Mental health: Culture, race, and ethnicity-Supplement to Mental health: A report of the Surgeon General (2001)*<sup>8</sup>
  - *In the Best Interests of All (2003)*<sup>9</sup>, the position paper of Children's Behavior Alliance;
  - *Achieving the Promise (2003)*,<sup>10</sup> 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)*<sup>11</sup>, the position paper of the School Mental Health Alliance.
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