

# ADHD-EUROPE STATEMENT TO DG SANCO MENTAL HEALTH POLICYMAKERS July 2009

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## Introduction

ADHD-Europe is a European umbrella organization comprising 27 AD/HD self-support organizations in 19 European countries. Our aim is to promote awareness about Attention-Deficit/Hyperactivity Disorder (more commonly known now as AD/HD) to combat the stigma surrounding this condition and the resulting discrimination that exists throughout Europe, which negatively affects the number of children, adolescents and adults who are being diagnosed and treated for AD/HD and/or coexisting psychiatric disorders.

We want to target policymakers in the European institutions and in the National governments so that people who are affected by this lifelong mental health disorder are given their basic human rights. We advocate for children and adolescents especially because the prognosis is much better for those who are diagnosed and treated at a young age.

We especially promote Early Intervention and Treatment so that there are fewer adults with pervasive and unmanageable mental health disorders in Europe in the future.

We believe that there is a great need for evidence-based information about AD/HD to be included in a Conference about Mental Health in Youth and Education. Current research shows that AD/HD is linked to psychiatric disorders in that those who have AD/HD are more likely than others to develop other psychiatric conditions as they progress through childhood and especially when they reach adulthood. The list of comorbid conditions include: Personality Disorders (PD), Depression, Anxiety Disorder, Addiction, Asperger's Syndrome, Eating and Sleeping disorders, among many others. If psychiatrists treat only the comorbid symptoms (co-existing psychiatric condition), the patient will not progress satisfactorily.

We are therefore pleased to be given the opportunity to make a written contribution in the form of a Statement to the DG SANCO Mental Health policymakers. We have gathered together a body of evidence-based background information about **Attention-Deficit/Hyperactivity Disorder (AD/HD)** for your review, as well as relevant excerpts from a number of Human Rights Declarations that have been made over the years.

There is a body of research available to us today to back up the position taken by ADHD-Europe as evidenced in this document. [Top of Document](#)

## What is AD/HD?

Attention Deficit Hyperactivity Disorder (or AD/HD) is defined as a developmentally inappropriate level of inattention and/or hyperactivity-impulsivity that is present before the age of seven years.

AD/HD is:

- frequent: 3 – 5 % of school-aged children; 1 – 3 % of the adults;
- disabling (social, behavioural, educational, professional etc.);

- a burden on the individual, family and society;
- complicated by additional problems in most cases.

Ideally, early and accurate detection in conjunction with appropriate treatment of AD/HD, support for the family and interventions/accommodations within the educational and professional systems are critical for an individual. The hyperactive or impulsive behaviours and attention deficit problems are often not in keeping with either the intellectual abilities or the developmental stages of the individual.

AD/HD is a neuropsychiatric disorder with a genetic risk (70-80 %), and is influenced by environmental factors. Genetic tendencies for AD/HD often interact with the environment in complex ways.

AD/HD is multifactorial in its etiology. First of all, there are some possible acquired biological factors related to intra-uterine exposure to alcohol or nicotine, low birth weight and brain infections (e.g. encephalitis). Modulating psychosocial factors such as family instability, parental mental health issues, poor competence in parenting, and low socioeconomic status **do not cause AD/HD** although they play an important role in its outcomes often making the symptoms and associated problems worse.

**Diagnosis should take place as soon as possible** with the ideal age being 6-7 with screening and detection already possible at kindergarten age. However, diagnosis may be undertaken up to any age. The screening and the clinical diagnosis of AD/HD by qualified healthcare professionals is based on a careful and complete review of an individual's history, overall patterns of behaviour and the symptoms of the disorder using the diagnostic criteria of DSM-IV TR.

These careful assessments follow existing protocols and may also include the observations of a child's parents and teachers. Evaluation of other possible causes of inattentive or hyperactive behaviour, as well as common coexisting conditions and co-morbidities, including learning disabilities, substance abuse, psychiatric disorders, depression, anxiety disorders and oppositional defiance disorder, is also undertaken depending on the behaviour and age of the individual.

A **multimodal treatment programme** must be individually tailored, continually monitored and optimised. Accompanying **psycho-education** forms the basis of all treatments for AD/HD. Another effective intervention includes **behavioural therapy** - for the individual and his or her family - in school as well as at home. In many cases, **medication** plays a central role in therapy. [Top of Document](#)

### **The Charter of Fundamental Rights of the European Union (Art. 35)**

*The Charter of Fundamental Rights of the European Union (Art. 35) provides the right for all members of society to benefit from medical treatment. There is a real need to include also the **educational and non-medical approaches as essential components of the treatment for ADHD.***

It is commonly accepted that AD/HD is under diagnosed and under treated in Europe; this being supported by literature from the Netherlands and the United Kingdom, which show problems with assessment, referral rates and diagnosis. Scepticism regarding the disorder also exists. Treatment practices across Europe vary considerably and health care professionals in some countries tend to be reluctant to prescribe medication even though medication is available. In some countries, medication is available but not reimbursed and in others it is not available, necessitating "cross border shopping" for specialist assistance and prescriptions, both situations which increase the financial burden on families. Local medical culture, individual experiences and clinical practice among many medical communities across Europe positively or negatively affect the care given to those affected by AD/HD.

In any case, it is crucial that children and families affected by AD/HD receive the treatment they deserve and need in order to lead as full and healthy lives as possible. To do this, a cultural change among healthcare professionals and educators is a necessary first step. By providing continuing professional development and further education to increase their awareness and knowledge about the diagnosis and treatment of AD/HD, they will be equipped with the skills and knowledge to improve the quality of care for children and adults. [Top of Document](#)

## **What are the Potential Long-term Effects of AD/HD and its Impact on Society?**

Certainly, **if not diagnosed or inappropriately diagnosed, the risk is that individuals receive no treatment at all or inappropriate treatment.** There is a plethora of evidence pointing to the likelihood that these individuals are at very high risk of increased difficulty in achieving success in life as well as developing some, or in some cases, all of the following:

- **Emotional problems:** low self esteem, depression (often leading to suicide)  
*Remark: it is noteworthy that ADHD is often one of the first causes of depression and often implicated in instances of suicide. Because of this, psychiatrists must develop an in depth knowledge of ADHD in order to thoroughly understand the issues surrounding the presenting symptomatology.*
- Development of serious **behavioural problems:** risk-taking behaviour, oppositional defiant and other conduct disorders, substance abuse, anti-social behaviour, criminal behaviour
- **Physical health problems:** substance abuse, accidents due to attention deficit and impulsivity, stress-related illnesses, cardiovascular disease ...
- **Educational problems:** poor academic performance due to underachievement and/or learning disabilities resulting in school failure; behavioural problems often leading to suspension (sometimes unjustified); leaving school early etc.
- **Relationship problems:** increased conflict at home between parents and/or siblings, difficulties with peers and/or colleagues, lack of or poor development of social skills, higher rates of marital difficulties and/or divorce etc.
- **Employment issues:** unemployment, frequent change of employment, frequent job loss due to behaviour (often unjustified), inadequate performance on the job ...
- Increased **cost burden** for society and individuals as a result of accidents, insurance claims, prolongation and increased complexity of treatment ...

In most cases there is a **chain reaction in the effects of AD/HD on an individual** with ensuing co-morbidities developing. Too often social exclusion results from an accumulation of the issues related to AD/HD.

### **Remarks**

*There are different outcomes possible in the adulthood of people affected by AD/HD.*

1. *Some adults are able to manage their daily lives successfully. They are capable of realizing the full potential of their lives, often aided by typical AD/HD-characteristics becoming their strength (e.g. creative and artistic ability, entrepreneurial ideas, dynamism etc.). If diagnosed and treated appropriately, there is an optimistic perspective that their health and quality of life will be maintained.*
2. *Many adults affected by AD/HD have to deal with problems on the social and psychological level, but they manage to cope, due to a lot of family support, community support and other resources depending on where they live within Europe.*
3. *Other adults are confronted with profound social and psychiatric problems, not able to cope or to compensate for their impairment. This is the target group for whom the mental health issues are so important.*

**Untreated or inappropriately treated AD/HD causes significant loss and creates excessive burden and expense to the health, economic, social, educational, as well as to the criminal and justice systems.**

Although more health economic research needs to be done on the increased costs to society, it is known that **early intervention - diagnosis, appropriate treatment and adequate support - can improve the individual's prognosis and thus will likely have a downstream cost-saving impact for governments.**

The priorities for the target group affected by AD/HD are:

- **Promoting health** for the group and their social environments;

- **Reducing the burden** of the disorder by adequate prevention, early diagnosis and appropriate treatment and
- **Addressing stigma, discrimination and social exclusion** while promoting human rights and dignity.

We want to stress that these topics were emphasised in the **Treaty of Maastricht** establishing the European Community (Ref. 17 - Consolidated version of the treaty establishing the European Community, 2002). With regard to the **European Charter of Fundamental Rights**, ADHD-Europe cites the existence of the right to the integration of persons with disabilities: "*The Union recognises and respects the rights of people with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community*".

#### **Conclusions from Research Presented at AD/HD International Congress Vienna May 2009**

- 1) AD/HD is a risk factor for other psychiatric disorders such as Personality Disorder (PD) and affective disorders;
- 2) AD/HD should be considered when treating depression and Personality Disorders;
- 3) Treatment should integrate AD/HD-oriented medication and psychotherapy;
- 4) AD/HD is a serious risk factor for affective disorders;
- 5) Take AD/HD into account in patients with brief recurrent depression and other affective disorders (see References).

***We urge you to take this Statement about AD/HD into account when formulating Mental Health policies and when taking steps to implement the European Pact for Mental Health and Well-being.***

***The implementation of the European Pact for Mental Health and Well-being would not be complete or, indeed, authentic if considerable attention is not given to the above mentioned points regarding Attention-Deficit/Hyperactivity Disorder (AD/HD) and the very real link between this disorder and the mental health conditions of most concern in Europe today.***

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## **Appendix 1: ADHD-Europe Declaration about AD/HD 2009**

ADHD-Europe has charted a Declaration about AD/HD, which will be signed by psychiatrists and psychologists across Europe and distributed during the European AD/HD Awareness Week 2009 (20-27 September) in an effort to spread evidence-based knowledge and awareness about this condition:

**Taking into consideration that** AD/HD can cause devastating consequences, including failure in school and the workplace, antisocial behaviour, encounters with the criminal justice system, interpersonal difficulties and substance abuse;

**Taking into consideration that** AD/HD is the most extensively studied mental disorder in children, affecting an estimated 3 to 7 percent of school-age children and an estimated 4 percent of adults across racial, ethnic and socioeconomic lines in Europe and worldwide;

**Taking into consideration that** scientific studies indicate that AD/HD in childhood is an indicator for a variety of mental disorders in adulthood, such as Personality Disorders, Depression, Anxiety and many stress related conditions that affect every area of a person's life;

**Taking into consideration that** the lack of understanding and public knowledge of AD/HD play a Significant role in the overwhelming numbers of both children and adults who have untreated AD/HD;

**Taking into consideration that** the lack of responsible reporting in the media and the dissemination of inaccurate and misleading information about AD/HD contributes to the large number of people who have not been diagnosed or treated for this condition despite the devastation that untreated AD/HD is causing in their lives and the lives of their loved ones;

**Taking into consideration that** the lack of awareness, knowledge and stigma surrounding the condition have a particularly detrimental effect on the diagnosis and treatment of the disorder;

**Taking into consideration** the need for adequate education about this disorder for healthcare Professionals across Europe so that they are capable of identifying, properly diagnosing and treating AD/HD in all its manifestations;

**Taking into consideration** the need also for a comprehensive psycho-education programme for educators, school administrators and employers across Europe so that they have awareness and knowledge of the condition and can give the appropriate help to those in their care who are affected by this disorder;

**Taking into consideration** the now well-documented fact that the symptoms of AD/HD can be significantly reduced and the quality of life improved if a proper comprehensive diagnosis and multimodal treatment plan is carried out;

**Taking all this into consideration, we urgently ask all policymakers, healthcare professionals, educators, the media and the general public to make sure that the basic human rights of all children, adolescents and adults who suffer from AD/HD are being met so that they are given the opportunity to live productive lives in spite of having a handicap that will be with them all their lives.**

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## **Appendix 2: Children's Rights**

### **1. Florence Declaration 2007**

#### Art. 3. The scale of the problem

Europe is facing massive challenges in child and adolescent mental health. Fortunately most people in Europe enjoy a high quality of life: according to the World Health Organization (WHO, 2001), 80% of young people report a good psychological well-being. However, one adolescent out of five has cognitive, emotional and behavioral difficulties and one adolescent out of eight suffers from a diagnosable mental disorder, and the prevalence is increasing decade by decade. Suicide associated with depression, substance abuse, eating disorders, conduct disorders, attention deficit hyperactivity disorders (ADHD) and post traumatic stress disorder (PTSD) in children are all deserving concerted action. Developmental psychiatric disorders rarely have a spontaneous remission and may cause difficult social adaptation or mental disorder in adult life if not early diagnosed and treated.

Child mental health is important in its own right, but it has also to be considered in the context of a lifespan approach: most adult mental disorders find their origin in childhood and adolescence and require early intervention and treatment. Mental disorders prevented in childhood are mental disorders prevented for life.

### **2. Convention on the Rights of the Child: U.N. General Assembly 1989**

<http://www.cirp.org/library/ethics/UN-convention/>

#### Article 19

1. States Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child.

#### Article 23

4. States Parties shall promote, in the spirit of international co-operation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.

### **3. Declaration of the Rights of the Child November 1959**

<http://www.unhcr.org/refworld/topic,459d17822,459d17a82,3ae6b38e3,0.html>

#### Article 7

The child is entitled to receive education, which shall be free and compulsory, at least in the elementary stages. He shall be given an education which will promote his general culture and enable him, on a basis of equal opportunity, to develop his abilities, his individual judgement, and his sense of moral and social responsibility, and to become a useful member of society. The best interests of the child shall be the guiding principle of those responsible for his education and guidance; that responsibility lies in the first place with his parents.

The child shall have full opportunity for play and recreation, which should be directed to the same purposes as education; society and the public authorities shall endeavour to promote the enjoyment of this right.

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